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# Professional Caregiving in Motor Neurone Disease: An Exploratory Mixed-Methods Study of Professional Well-Being and Support Needs

A dissertation submitted to Trinity College Dublin for the degree of Doctor of Philosophy (PhD) in Clinical Medicine

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## Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work. I confirm that the work has been completed in full compliance with relevant university policies, including the Academic Integrity policy, the Trinity Policy on Good Research Practice, and the guidance on AI and GenAI in Teaching, Learning, Assessment and Research.

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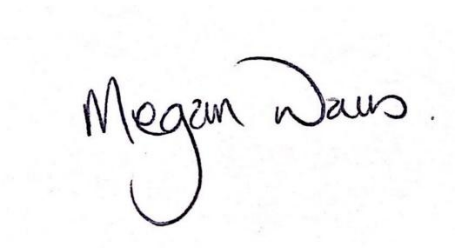

**Signed:**

**Date:** 23.01.2026

# Summary

This research used an exploratory sequential mixed methods design across four phases to examine the experiences, professional well-being, and support needs of healthcare professionals providing care to people living with motor neurone disease (MND) and their families. Phase One, a scoping review found that MND care was perceived as distinctive, highly individualised, and more intensive than care for other patient populations. Professionals' capacity to deliver optimal care was influenced by interacting factors, including patient complexity, informal caregiver involvement, multidisciplinary team support, and organisational context. Although the emotional impact of MND care was evident, professional well-being was not directly measured and was seldom the primary focus of identified studies. Phase Two used focus groups with Irish healthcare professionals and reflexive thematic analysis. Qualitative data highlighted the complex emotional and relational landscape of MND care across the disease trajectory. While participants expressed strong commitment to providing compassionate, person-centred care, they were also challenged by uncertainty, emotional burden, helplessness, and systemic constraints. Findings highlighted opportunities for professional education and development, interpersonal support, and organisational changes to sustain both professionals' well-being and their ability to deliver consistent, compassionate care across the illness trajectory. Phase Three was a cross-sectional online survey of healthcare professionals working in MND services across Europe. Sixty-seven percent reported experiencing moral distress, which was significantly associated with reduced professional quality of life, including higher burnout and secondary traumatic stress, and with intentions to leave or change roles. Despite these challenges, compassion satisfaction was high and negatively associated with burnout, while informal collegial support and multidisciplinary teamwork emerged as key protective factors. Phase Four integrated findings across all phases, demonstrating that healthcare professionals' experiences and well-being can be shaped by multilevel influences spanning system, organisational, interpersonal, and individual domains. These findings underscore the need for multifaceted, integrated approaches to supporting professional well-being and sustaining high quality MND patient and family care.

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Thank you all, I am incredibly grateful for this experience, and you have each played a massive part in that over the last number of years.

# Abstract

**Introduction**: Motor neurone disease (MND) is a complex, incurable neurodegenerative condition that imposes profound physical, psychological, and social burdens on affected individuals and their families. In the absence of curative treatments, healthcare professionals play a pivotal role in delivering compassionate, supportive care focused on symptom management and quality of life. While healthcare professional well-being is increasingly recognised as central to the patient experience and workforce sustainability, the experiences of professionals working with people affected by MND remain underrepresented in the literature, with limited understanding of the emotional and psychological impact of this work on their professional well-being or the supports required to sustain them in these roles and in providing compassionate MND care.

**Aim:** This PhD aimed to develop an understanding of the experiences of healthcare professionals working with people living with MND and their families, examine the impact of this work on personal and professional well-being, and inform practical recommendations to support professional well-being and workforce sustainability.

**Method:** An exploratory sequential mixed methods design was employed across four interconnected phases. Phase One comprised a scoping review of the existing literature. Phase Two involved focus groups with healthcare professionals working in MND care in Ireland, analysed using reflexive thematic analysis. Phase Three consisted of a cross-sectional online survey of healthcare professionals providing MND care across Europe. Phase Four integrated findings from the preceding phases using the Extended Pillar Integration Process and informed actionable, practice-relevant recommendations.

**Results**: Phase One synthesised findings from 51 existing sources and found that MND care was perceived as distinctive, more intensive, and highly individualised compared with other patient populations. Healthcare professionals' ability to provide optimal care was influenced by patient complexity, informal caregiver involvement, multidisciplinary team support, and organisational context. Although

the emotional impact of MND care was evident, professional well-being was not directly measured and was seldom the primary focus of the identified existing literature.

Phase Two recruited 43 healthcare professionals across the Irish healthcare system and highlighted the emotionally demanding and relational nature of MND care across the illness trajectory. While clinicians described strong commitment to compassionate, person-centred care, they were also challenged by feelings of uncertainty and helplessness, emotional burden and systemic constraints. Findings identified opportunities for enhanced professional education and development, interpersonal organisational level supports to sustain professional well-being and their ability to deliver consistent, compassionate care.

Phase Three found that 67% of 230 European healthcare professionals experienced moral distress in their work with MND patients and families. This was significantly associated with reduced professional quality of life, including higher burnout and secondary traumatic stress, and with intentions to leave or change roles. Despite these challenges, compassion satisfaction was high and negatively associated with burnout, while informal collegial support and multidisciplinary teamwork emerged as key protective factors.

Phase four integrated findings across each of the three preceding phases, outlining how healthcare professionals' experiences and well-being can be shaped by multilevel influences spanning system, organisational, interpersonal, and individual domains. Corresponding opportunities for support, education and intervention were identified to enhance professional well-being and professional quality of life in this context.

**Conclusion:** This research has identified that working with people and families affected by MND can both positively and negatively affect the personal and professional well-being of healthcare professionals involved in providing their care. While the practical, emotional and ethical complexities of these roles can place professionals at risk of moral distress, compassion fatigue and burnout, many derive substantial meaning, purpose, and compassion satisfaction from their work.

Supporting the well-being of healthcare professionals providing MND care requires multifaceted approaches spanning system and organisational change, interpersonal supports, and individual-level education and intervention. Future work is needed to both develop and test the effectiveness of interventions and approaches aimed at reducing the impact of working with MND on professional well-being and quality of life.

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# List of Abbreviations

AAC – Augmentative and Alternative Communication

AHP – Allied Healthcare Professional

ALS – Amyotrophic Lateral Sclerosis

ATSS – Assistive Technology and Specialist Seating Service

BRCS – Brief Resilient Coping Scale

CF – Compassion Fatigue

CROSS – Consensus-based Guideline for The Reporting of Survey Studies

CS – Compassion Satisfaction

DPO – Data Protection Officer

EI – Emotional Intelligence

ePIP – Extended Pillar Integration Process

HCP – Healthcare Professional

HSE – Health Service Executive

JBI – Joanna Briggs Institute

MD – Moral Distress

MD Thermometer – Moral Distress Thermometer

Mdn – Median

MDT – Multidisciplinary Team

MND – Motor Neurone Disease

MSW - Medical Social Worker

OT - Occupational Therapist

PlwMND – People Living with MND

PRISMA-ScR - Preferred Reporting Items for Systematic reviews and Meta-Analyses – Extension for Scoping Reviews

ProQOL – Professional Quality of Life Scale

PT – Physiotherapist

RTA – Reflexive Thematic Analysis

RTARG – Reflexive Thematic Analysis Reporting Guidelines

SDM – Shared Decision Making

SLT - Speech and Language Therapist

STS – Secondary Traumatic Stress

WHO – World Health Organisation

## Publications and Dissemination

- Scoping Review Protocol – Registered on Open Science Framework (https://osf.io/gkjme).

**Journal Publications:**

- Walls, M., Claffey, A., Mockler, D. & Galvin, M. 2024. Working with People Living with Motor Neurone Disease and the Impact on Professionals' Emotional and Psychological Well-Being: A Scoping Review. *Palliative Medicine*, p.02692163241291745. DOI: https://doiorg.elib.tcd.ie/10.1177/02692163241291745
- Walls, M., Claffey, A. & Galvin, M. 2026. Moral Distress in Healthcare Professionals Working with Motor Neurone Disease – Accepted for publication in Palliative and Supportive Care on the 19.01.2026. Not available online at time of thesis submission.

**Planned Publications:**

- Walls, M., Claffey, A. & Galvin, M. Healthcare Professionals Experiences of Working with Motor Neurone Disease in Irish Healthcare Services – A Qualitative Study. – Invited to submit a manuscript for the Special Issue "*Improving Care for People Living with ALS/MND*" in the Journal Healthcare by June 2026.

**Conference Oral Presentations**

- A Qualitative Study Exploring Healthcare Professionals Experiences of Working with Motor Neurone Disease (MND) in Irish Healthcare Services. Irish Association for Palliative Care 24th Annual Education and Research Seminar 2025. Dublin, Ireland. 11th February 2025. (Highly commended presentation)
- Moral Distress in Healthcare Professionals Working with ALS/MND. Allied Professionals Forum. Toronto, Canada. 2nd December 2025.

**Conference Poster Presentations:**

- Walls, M., Claffey, A. & Galvin, M. "*Healthcare Professionals' experience of providing care for people with motor neurone disease (MND) and their family caregivers: A scoping literature review*". Presented at the 3rd International Research Seminar of the European Association for Palliative Care Reference Group on Public Health and Palliative Care. Assembly Buildings, Belfast. 16th-17th November 2023.
- Walls, M., Claffey, A. & Galvin, M. "*The Healthcare Professionals Perspective on Caregiving for Motor Neurone Disease - What Do We Know About the Emotional and Psychological Impact? Findings from a Scoping Literature Review"*. Presented at the 2023 Alliance Meeting & Allied Professionals Forum of the International Alliance of ALS/MND Associations. Basel, Switzerland. 2nd – 5th December 2023.
- Walls, M., Claffey, A. & Galvin, M. "*Healthcare Professionals' experience of providing care for people with motor neurone disease (MND) and their family caregivers: A scoping literature review*". Presented at the 34th International Symposium on ALS/MND. Basel, Switzerland. 6th-8th December 2023.
- Walls, M., Claffey, A. & Galvin, M. "A Qualitative Study Exploring Healthcare Professionals Experiences of Working with Motor Neurone Disease (MND) in Irish Healthcare Services". Presented at the 35th International Symposium on ALS/MND. Montreal, Canada. 6th- 8th December 2024.
- Walls, M., Claffey, A. & Galvin, M. "A Qualitative Study Exploring Healthcare Professionals Experiences of Working with Motor Neurone Disease (MND) in Irish Healthcare Services".
  13th Annual Palliative Care Research Network Symposium. Stormont, Belfast. 14th November 2024.
- Walls, M., Claffey, A. & Galvin, M. "Experiences of healthcare professionals in their work with individuals living with motor neurone disease in specialist palliative care in Ireland: A qualitative study". 19th World Congress of the European Association for Palliative Care. Helsinki, Finland. 29th – 31st May 2025.

## Structure of the Thesis

**Chapter One: Introduction**

Provides an overview of the background and rationale for the research, identifies key knowledge gaps, and outlines the overarching aim of the study.

**Chapter Two: Methodology**

Describes the methodological approach underpinning the research, outlining the rationale for adopting a sequential mixed-methods research design and how this was rigorously applied across all phases of the research. The four distinct but interlinked phases of the research are outlined and introduced.

**Chapter Three: Phase One - Scoping Review**

Presents the process and findings of a scoping review that synthesised existing literature on healthcare professionals' experiences of working with MND and the impact of this work on their emotional and psychological well-being.

**Chapter Four: Phase Two - Qualitative Focus Group Study**

Presents the qualitative methods and findings from a study exploring the challenges, rewards, emotional and psychological experiences, and perceived supports among Irish healthcare professionals working with MND across key national services.

**Chapter Five: Phase Three - Cross-Sectional Online Survey Study**

Presents the methods and findings from an international online survey of the European MND workforce, examining moral distress, professional quality of life, workforce retention, and absenteeism, resilient coping and identifying factors perceived as supportive for sustaining engagement in MND patient and family care.

**Chapter Six: Phase Four – Extended Pillar Integration Process**

Presents the systematic application of the Extended Pillar Integration Process to integrate and synthesise findings from Phase One (scoping review), Phase Two (qualitative focus group study), and Phase Three (cross sectional online survey), generating practical, evidence-informed recommendations relevant to clinical practice.

**Chapter Seven: Conclusion**

Outlines the novel contributions and key findings from this research, implications of the research for practice, policy, and future investigation, provides the key strengths and limitations of the research, and overall conclusions.

## A Note on Language Used in this Thesis

Motor Neurone Disease (MND) is also commonly referred to as Amyotrophic Lateral Sclerosis (ALS), which is the most prevalent form of the condition. While the term ALS is more widely used in some regions internationally, MND is the preferred and more commonly adopted term in the European context. Throughout this thesis, the term MND is used to refer to the condition. However, ALS is retained where this reflects the terminology used in studies included in the scoping review, and both terms were used in the design of the online survey questions. Consequently, references to the condition as ALS may appear in certain sections of this thesis.

Throughout this thesis, services are often referred to as MND specific services or non-MND specific services. MND specific services are those designed exclusively to provide care and support for people living with MND and their families, including MND charity organisations and specialist MND multidisciplinary clinics. In contrast, non-MND specific services are those in which professionals care for people with MND as part of a broader remit, but where the service is not specifically designed for this population. These include palliative care, primary care, and residential care services.

# Chapter 1: Introduction

This chapter provides the background context and outlines the key concepts and foundational ideas central to this thesis. It begins by providing an overview of Motor Neurone Disease (MND) as a complex, progressive neurodegenerative disorder that imposes profound physical, psychological, and social challenges on those living with the condition, as well as their families. Current best-practice guidelines for the clinical management of MND are outlined, highlighting the pivotal role healthcare professionals (HCPs) play in optimising symptom control, supporting psychosocial adjustment, and enhancing overall quality of life for individuals affected by this challenging disease.

The chapter then introduces concepts of HCP well-being and professional quality of life, drawing on evidence from other areas of intensive and emotionally demanding clinical practice, and considers their potential application to MND care. Indicators of workforce engagement and well-being such as absenteeism, retention, and turnover are discussed as measures of occupational well-being, that can have implications for service sustainability and care quality.

Finally, national and international occupational health frameworks and workplace well-being policies are reviewed, reflecting a recent shift in organisational priorities towards supporting the health and well-being of the healthcare workforce. This focus is increasingly recognised as fundamental to the delivery of safe, effective, and sustainable care. Collectively, these sections provide the conceptual, empirical, and contextual foundation for this study, emphasising the relevance of the topic and the need for greater attention to the potential impact of working with MND on the professional well-being of HCPs.

## 1.1 Motor Neurone Disease

Motor neurone disease (MND) is a progressive neurodegenerative disorder characterised by degeneration of both upper and lower motor neurones in the brain

and spinal cord. Neurone degeneration results in weakening of the skeletal muscles that control movement, speech, swallowing, and respiration, leading to profound disability and, ultimately, death (Bäumer, Talbot and Turner, 2014). Respiratory failure is the most common cause of death and typically occurs within 2–4 years of symptom onset (Liu *et al.*, 2025). While initially considered an exclusively motor disorder, it is now well established that cognitive impairment and behavioral change are common features of MND, affecting up to 50% of people living with the condition and approximately 15% present with concomitant behavioral variant frontotemporal dementia (ALS-FTD) (Rusina, Vandenberghe and Bruffaerts, 2021). Recent studies have shown that the mean or median age of MND onset is between 51- 66 years, meaning that the condition typically affects people in middle adulthood, during their working and family-active years, adding to the social and emotional impact of the disease (Longinetti and Fang, 2019; Liu *et al.*, 2025).

Although MND is classified as a rare disease, defined in Europe as having a prevalence below 1 in 2,000 people (EURORDIS-Rare Diseases Europe, 2025), its incidence is comparable to that of conditions such as multiple sclerosis (Khan and Hashim, 2025), which are not considered rare. This is largely due to shorted survival with MND, which reduces overall prevalence. In Europe the incidence of MND is 2–3 per 100,000, and the prevalence remains significantly below the European rare-disease threshold at 3-11 per 100,000 (Wolfson *et al.*, 2023). In Ireland, there are approximately 150 new diagnoses each year and 400 people living with MND (plwMND) at any one time (IMNDA, 2023). Although absolute numbers are small, MND is widely regarded as the most devastating adult-onset neurodegenerative condition (Bäumer, Talbot and Turner, 2014). The number of plwMND is also increasing, driven by population ageing, earlier disease detection, improved access to specialist care, and multidisciplinary symptom-management interventions that extend survival (Hardiman *et al.*, 2017; De Jongh *et al.*, 2021). The associated physical, psychosocial, and socioeconomic burden is substantial for patients, families, and health systems, particularly in the later stages of the illness (Turner and Atkin, 2012; Heinrich *et al.*, 2023).

MND is a strikingly heterogeneous disease, both clinically and pathologically. The most common form is amyotrophic lateral sclerosis (ALS), accounting for approximately 70% of cases (Hardiman, Lefter and Galvin, 2021). ALS is characterised by combined upper and lower motor neurone degeneration and is the most fatal and debilitating of all MND subtypes. Clinically, ALS may present as (1) limb-onset, typically beginning with unilateral muscle weakness, wasting, spasticity or cramps in either the upper or lower limbs; (2) bulbar-onset, with early speech or swallowing difficulties; or (3) respiratory-onset, where initial symptoms are related to breathing difficulties (Hardiman *et al.*, 2017). Less common classifications include primary lateral sclerosis (PLS) (1–3%), involving pure upper motor neurone dysfunction; progressive muscular atrophy (PMA) (5%) with selective lower motor neurone involvement, and progressive bulbar palsy (PBP) (4–8%), characterised by a prolonged period of isolated bulbar symptoms with relative preservation of limb strength (Dharmadasa *et al.*, 2017).

This marked clinical and pathological variability poses several significant challenges. It often leads to diagnostic delays and misdiagnoses, particularly in atypical or slowly progressive cases (Reynolds and Chhetri, 2024). In Ireland, the median delay from symptom onset to confirmed diagnosis is approximately 11 months, resulting in delayed access to specialist care and evidence-based interventions (Galvin *et al.*, 2017). Heterogeneity also complicates prognostication, as disease progression rates vary widely between individuals and subtypes (Din Abdul Jabbar *et al.*, 2024). The unpredictable course and variable symptom profile can amplify psychological distress and decisional uncertainty for patients and caregivers (Harris et al., 2018). The absence of any disease-modifying or curative treatments can significantly diminish hope for those living with MND (Cheng *et al.*, 2018). This is further compounded by the considerable variability in disease phenotype and trajectory, which poses major challenges for clinical trial design, making it difficult to identify homogeneous cohorts, define meaningful endpoints, and interpret treatment effects (Van Eijk *et al.*, 2021).

In addition to clinical and pathological heterogeneity and prognostic uncertainty, the aetiology of MND remains unknown in most cases, with only around 5–10% of cases

attributable to familial or clearly genetic forms (González-Sánchez, Ramírez-Expósito and Martínez-Martos, 2025). In Europe, riluzole remains the standard disease-modifying therapy, but offers only a modest three month survival benefit (Dharmadasa and Kiernan, 2018). Since 2024, Tofersen has also been authorised under exceptional circumstances for adults with SOD1-mutation ALS, a small genetic subset, marking the first genotype-specific approval in the EU (O'Brien and Shaw, 2024). Current care prioritises pharmacological and non-pharmacological symptom management approaches to reduce disease burden and optimise quality of life (Hobson and McDermott, 2016). Respiratory support with non-invasive ventilation can extend survival, and enteral feeding may help maintain nutritional intake when indicated (Goyal and Mozaffar, 2014; Cheng *et al.*, 2018). The absence of a clear aetiology, the scarcity of broadly effective disease-modifying therapies, and the guarded prognosis can make the disclosure of an MND diagnosis particularly challenging for clinicians, who are tasked with supporting patients and families come to terms with a palliative care trajectory and the terminal nature of this disease from time of diagnosis (Aoun *et al.*, 2016; Anestis *et al.*, 2021).

### 1.1.1 Multidisciplinary Care – Best Practice Guidelines

The multitude of co-occurring, progressive, and evolving symptoms arising from motor neurone degeneration, together with extra-motor and psychosocial challenges, necessitates input from a broad multidisciplinary team (MDT) and coordinated care across multiple services. Best-practice guidelines from Europe, Canada, the United Kingdom, and New Zealand unanimously endorse a clinic-based specialist MDT model for the delivery of MND care (NICE, 2016; Shoesmith *et al.*, 2020; MND New Zealand, 2022; Van Damme *et al.*, 2024). This model is centred on a tertiary specialist MND team that provides structured outreach to the community between clinic visits. At a minimum, the team should include a neurologist, specialist nurse, dietitian, physiotherapist, occupational therapist, respiratory physiologist (or another clinician trained to assess respiratory function), and a speech and language therapist. The frequency of MDT review should be tailored to individual patient needs

and disease trajectory, recognising that MND can progress rapidly and requires repeated assessment with prompt responses to emerging issues. Effective care relies on strong communication and coordination between the tertiary team, primary care, palliative care, community services, and other specialist providers, including respiratory ventilation services, wheelchair services, assistive technology, and augmentative and alternative communication (AAC) (NICE, 2016; Shoesmith *et al.*, 2020; MND New Zealand, 2022; Van Damme *et al.*, 2024).

Numerous studies have reported benefits from attending specialist MDT clinics, including fewer hospital admissions, shorter inpatient stays compared with general neurology care (Chio, 2006), and a survival advantage, greatest in bulbar-onset MND (de Almeida, do Carmo Santana and de Carvalho, 2021). Van den Berg *et al.* (2005) also found that clinic attendees experienced better quality of life, especially in social functioning and mental health, although no significant benefit was observed for caregivers. These benefits are thought to result from timelier and coordinated interventions, including earlier and consistent use of riluzole and non-invasive ventilation, proactive nutritional assessment with earlier gastrostomy when indicated, systematic symptom monitoring and management, and prompt involvement of palliative care for complex needs (Stephens *et al.*, 2015; Paipa *et al.*, 2019).

Guidelines further emphasise the importance of attending to the needs and emotional well-being of caregivers, recognising the substantial physical, psychological, and social burden borne by families and informal carers. For example, the MND New Zealand (2022) guideline explicitly recommends providing protected time for caregivers to discuss the impact of the disease with the care team. Notably, this guideline is also unique in acknowledging the emotional and ethical challenges faced by HCPs, recognising that clinicians working with MND also require supports when working with the complexities of MND patient care:

*"MND creates many challenges for professionals and can arouse strong emotions. These can include frustration, powerlessness, inadequacy, and sadness. It highlights attitudes to issues related to disability, quality of life and measures taken to prolong life. Good interdisciplinary teamwork is necessary to provide support and*

*opportunities to discuss concerns and responses to difficult situations. Support, in the form of regular clinical supervision, is recommended"* (MND New Zealand, 2022, p.46).

Although HCP well-being is closely linked to the quality and sustainability of patient care, existing research and MND clinical management guidelines have largely centered on patients and informal caregivers. Consequently, the perspectives, coping strategies, and support needs of HCPs remain insufficiently explored, despite the significant demands associated with delivering complex, multidisciplinary care to plwMND and their informal caregivers.

### 1.1.2 Motor Neurone Disease Services in Ireland

In line with European guidelines, MND care in Ireland is primarily delivered through the national multidisciplinary MND clinic at the National Centre for Neuroscience, Beaumont Hospital, Dublin. The clinic is closely affiliated with the Irish Motor Neurone Disease Association (IMNDA), the only MND-specific voluntary organisation, which provides nursing and support services for all plwMND in the Republic of Ireland. Operating on a weekly basis, the national clinic serves over 80% of Irish MND patients, complemented by two regional satellite MDT clinics in Galway and Cork that run monthly to support local populations. The Beaumont service is also affiliated with Trinity College Dublin's Academic Unit of Neurology. Two influential studies have demonstrated an approximate nine-month survival advantage for patients attending this national MND MDT clinic service (Traynor, 2003; Rooney *et al.*, 2015).

The national clinic comprises a team of approximately 20 professionals, including senior neurologists, clinical fellows, specialist nurses, clinical trials and research staff, and allied health specialists (occupational therapy, physiotherapy, speech and language therapy, dietetics, social work, and neuropsychology). This expert team works closely with community services and specialist palliative care to coordinate comprehensive supportive care. Patients requiring advanced communication or environmental control technologies are referred to specialist technology services. In

Ireland, home-care assistance is provided through the HSE (Health Service Executive) Home Support Service, while residential care is publicly funded via the Fair Deal scheme; private providers also frequently contribute to both residential and home care for plwMND (Hardiman, Lefter and Galvin, 2021). A frequently cited challenge, however, is integrating these many services and ensuring effective communication and handover between professionals and teams (Hogden *et al.*, 2012). Stakeholders vary in their experience, exposure, and knowledge of MND, yet each plays a distinct and crucial role in supporting patients and families.

To date, no research in Ireland has examined the experiences or perspectives of HCPs involved in the care of individuals and families affected by MND, nor how they collaborate in the delivery of care for this complex condition. Addressing this critical gap, a key objective of the present study is to explore the experiences, perspectives, and support needs of the multidisciplinary teams and services providing MND care in Ireland. By capturing both shared and service-specific perspectives, this research seeks to develop a nuanced understanding of individual, professional and organisational factors that influence HCPs' well-being and their capacity to deliver compassionate, high-quality care to plwMND and their families.

## 1.2 Healthcare Professional Well-Being and Quality of Life

Healthcare professional well-being and professional quality of life are best understood as dynamically interrelated constructs, that reflect how clinicians' day-to-day psychological and occupational well-being both shapes, and is shaped by, their broader experiences of work (Merlo *et al.*, 2024).

HCP well-being is specifically understood as a work-related construct, shaped by levels of job satisfaction, a sense of meaning and purpose in one's role, engagement in daily tasks, the quality of working life, and experiences of professional fulfilment (National Academies of Sciences, Engineering, and Medicine, 2019). It can further be defined as *"an integrative concept that characterises quality of life with respect to an individual's health and work-related environmental, organisational, and psychosocial*

*factors. The experience of positive perceptions and the presence of constructive conditions at work and beyond that enables workers to thrive and achieve their full potential*" (Chari et al., 2018, p. 590). In parallel, professional quality of life is a concept that reflects both the positive and negative emotional consequences of caring work, encompassing the satisfaction derived from helping others alongside the emotional costs of caregiving (Stamm, 2010).

The growing global concern over the psychological well-being of HCPs has escalated following the COVID-19 pandemic, which profoundly disrupted health systems worldwide and placed exceptional strain on the mental health and well-being of healthcare workers (Søvold *et al.*, 2021; Ooms *et al.*, 2022). Beyond pandemic-related pressures, caring for individuals with complex, progressive, or life-limiting conditions presents enduring psychological and emotional challenges (Arantzamendi *et al.*, 2024). These experiences are often conceptualised through constructs such as burnout, compassion fatigue, secondary traumatic stress, and moral distress, each capturing distinct yet interrelated dimensions of occupational strain and professional well-being (Hussain, 2021). Collectively, these constructs illustrate the cumulative effects of chronic workplace stress, repeated exposure to patient suffering, and ethically challenging situations that may conflict with personal or professional values. Although these phenomena are theoretically distinct, they frequently co-occur within complex care environments, reflecting the multifaceted nature of emotional and psychological burden in healthcare practice (Molu, 2023).

These challenges are likely to be particularly salient in MND care, where the progressive and terminal nature of the condition, high levels of patient dependency, and intensive multidisciplinary coordination are just some factors that can intensify pressures on HCPs. Despite growing recognition of these challenges, research exploring professional well-being in MND services remains limited. Addressing this gap, the present study will adopt an exploratory approach to investigate how working with patients and families affected by MND may influence the well-being of HCPs and teams, drawing on established frameworks from other ethically and emotionally complex areas of healthcare practice.

### 1.2.1 Burnout

Burnout is an occupational phenomenon that results from chronic workplace stress (Edú-Valsania, Laguía and Moriano, 2022) and from work-environment and role conditions that progressively erode a person's capacity to care (Stamm, 2010). Maslach's three-dimensional framework remains the most widely used model for understanding and measuring burnout (Maslach, 1998; Maslach and Leiter, 2016). The three key dimensions of this are an overwhelming exhaustion, feelings of cynicism and detachment from the job, and a sense of ineffectiveness and lack of accomplishment (Maslach and Leiter, 2016). Burnout arises from a combination of organisational and individual factors. Organisational factors, such as workload, emotional demands, and role conflict, are some of the primary drivers, while individual factors, such as coping strategies and personality factors, can moderate its impact (Demerouti, 2024). It is, however, important to recognise that burnout reflects a response to work conditions rather than an inherent personal weakness (World Health Organisation, 2019).

The Job Demands–Resources (JD-R) model provides a widely used framework for understanding how work conditions influence professional well-being (Bakker, Demerouti and Verbeke, 2004; Bakker and Demerouti, 2007). According to this model, excessive or sustained job demands can deplete physical and psychological resources, increasing the risk of burnout. Conversely, job and personal resources, such as social support, autonomy, feedback, and self-efficacy, can buffer these effects, fostering resilience, engagement, and motivation (Lesener, Gusy and Wolter, 2019). The JD-R model conceptualises burnout as a dynamic imbalance between demands and resources, highlighting how interventions such as improved staffing, supervisory support, or professional development can mitigate the risk (Bakker and Demerouti, 2014). Extensively applied in healthcare research, the framework offers a useful lens for examining how organisational conditions and individual coping resources interact to shape burnout among health professionals (Tomo and De Simone, 2019; Barello *et al.*, 2021; Zhou *et al.*, 2022; Gynning *et al.*, 2024).

In healthcare research burnout is commonly assessed with validated instruments such as the Maslach Burnout Inventory (MBI) (Maslach and Jackson, 1981), the Copenhagen Burnout Inventory (CBI) (Kristensen *et al.*, 2018), and with related constructs, using the Professional Quality of Life Scale (ProQOL) (Stamm, 2010). However, heterogeneity in tools and threshold criteria used across studies limits comparability and complicates efforts to determine the true prevalence and severity of burnout among HCPs (Alahmari *et al.*, 2022). Reported prevalence rates can vary widely, for example, a systematic review of palliative care professionals found burnout rates ranging from 3% to 66%, reflecting differences in work setting, role, workload, and support structures, but also in how it was measured between studies (Dijxhoorn *et al.*, 2021). However, HCPs are considered at greater risk of burnout than the general population, in particular those working in emotionally demanding care environments (Nagle *et al.*, 2024).

Burnout has wide ranging implications for both the individuals affected and the organisations in which they work (Salvagioni *et al.*, 2017). Initially manifesting as psychological strain, prolonged burnout can negatively impact physical health and behaviour. These individual effects often translate into organisational consequences, including reduced motivation and performance, compromised quality of care, increased sickness absence, and higher turnover intentions or likelihood of leaving the profession (Salyers *et al.*, 2017; Bridgeman, Bridgeman and Barone, 2018).

Evidence specific to the MND workforce or those working with MND is limited. In a qualitative study of neurologists working with MND, 27% of 11 participants reported experiencing burnout and 64% perceived themselves to be at risk; those reporting burnout were among the youngest and had fewer years of experience, suggesting that greater experience may be associated with more effective coping (Hennessey, 2016). Similarly, Lerum, Solbraekke and Frich (2017) identified multiple challenges and sources of professional stress when providing care for plwMND in primary care, including systemic pressures, time constraints, coordination difficulties, and the need to tailor care to rapidly changing, individual needs. They also noted staffing continuity issues and that some professionals avoided working with this population

due to the perceived intensity of demand (Lerum, Solbraekke and Frich, 2017). Although burnout was not examined explicitly, these findings point to working conditions marked by sustained workload pressure and limited access to adequate resources, factors that are widely recognised as significant contributors to burnout risk.

At the outset of this project, the prevalence of burnout within the MND workforce had not been well-documented. However, two very recent studies have begun to address this gap. In the UK, 26% of clinical nurse specialists and allied health professionals (AHPs) working with MND were found to be at medium to high risk of burnout (Chau *et al.*, 2025), while in Canada, 47% of MND (referred to as ALS in the study) HCPs were identified as experiencing burnout (Hansen, Burton-MacLeod and Schellenberg, 2024). These findings hightlight the growing recognition of burnout as a significant and emerging concern within the MND workforce. They underscore the need for further research to establish prevalence across diverse care contexts, identify key occupational and organisational risk factors, and inform the identification of targeted, context-sensitive strategies to prevent burnout and support the long-term well-being of professionals working in this demanding field.

### 1.2.2 Compassion Fatigue

Compassion fatigue, a concept that was introduced in the 1990s by Charles Figley, is described as the "*cost of caring*" for individuals in emotional pain (Figley, 1995). It refers to a state of emotional, physical, and psychological exhaustion resulting from prolonged exposure to others' suffering and the sustained use of empathy in caregiving roles (Figley, 1995). A closely related construct is secondary traumatic stress (STS), also known as vicarious trauma, which develops when individuals are indirectly exposed to others' traumatic experiences through their professional work (Figley, 1999). STS manifests in symptom clusters similar to post-traumatic stress disorder, including intrusive thoughts, avoidance, negative changes in mood and cognition, and hyperarousal (Baird and Kracen, 2006). Unlike burnout, which

develops gradually due to chronic workplace stress, STS can emerge suddenly following exposure to a particularly distressing event and is specific to the emotional impact of witnessing others' trauma. Although STS and burnout share overlapping features, since repeated exposure to suffering can deplete emotional resources, they are recognised as distinct constructs (Cieslak *et al.*, 2014). Compassion fatigue is often used as an umbrella concept encompassing both STS and burnout within caregiving contexts (Stamm, 2010). Research into compassion fatigue and related interventions aims to promote resilience and well-being among professional caregivers, supporting their ability to recover and maintain effective functioning both professionally and personally after repeated exposure to the pain and suffering of others (Noor *et al.*, 2025).

Compassion fatigue is most commonly measured using The Professional Quality of Life Scale (ProQOL – Version 5) in healthcare research (Baqeas, Davis and Copnell, 2021). It evolved from earlier instruments designed to assess the emotional impact of caregiving, including Figley's Compassion Fatigue Self-Test (1995) and Stamm's Compassion Fatigue Scale - Revised (1996). Stamm (2010) subsequently refined the measure to capture not only the negative consequences of caregiving but also to provide a more balanced appraisal of its inherent costs and rewards (1.3.1 Compassion Satisfaction). Other available measures include the Compassion Fatigue Inventory (Eng, Nordström and Schad, 2021) and the Secondary Traumatic Stress Scale (Bride *et al.*, 2004), though these have been less frequently applied in healthcare research.

Professionals who work with dying patients, manage heavy caseloads, experience moral distress, or are repeatedly exposed to trauma and suffering are at increased risk of compassion fatigue (Baqeas, Davis and Copnell, 2021). Additional risk factors include a poor team climate, a personal history of trauma or grief, and reliance on maladaptive coping strategies (Sorenson *et al.*, 2016). Compassion fatigue can manifest as feelings of dread when working with certain patients or in specific situations, often leading to avoidance behaviours (Stoewen, 2020). It can also reduce clinicians' capacity for empathy and engagement, thereby compromising the quality of patient care provided (Liu *et al.*, 2024). The consequences of compassion fatigue

also extend beyond individual well-being and burnout and have been linked to higher rates of absenteeism and staff turnover in healthcare settings (Stoewen, 2020).

MND is a devastating condition marked by a cascade of losses for both the person affected and their family (Pinto *et al.*, 2021). Delivering this terminal diagnosis is often a profoundly emotional experience for neurologists (Aoun *et al.*, 2016; Anestis *et al.*, 2021). A recent review also shows that sustained exposure to patient suffering exposes MND nurses to complex emotional challenges across the care trajectory (Artioli *et al.*, 2025). Despite the clear presence of risk factors for compassion fatigue, there has been limited empirical attention to how this phenomenon may affect professionals who care for or interact closely with MND patients and their families. Understanding potential contributing factors and the impact of compassion fatigue in this context is important, given its potential to affect both workforce well-being, sustainability and the quality of patient care.

### 1.2.3 Moral Distress

Moral distress (MD) was first introduced by Andrew Jameton to describe the psychological distress experienced by nurses "*when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action*" (Jameton, 1984) . During the 1990s and 2000s, this concept was operationalised through measurement tools, most notably Corley's Moral Distress Scale (MDS), which helped shift MD from a purely conceptual term to something that could be measured in practice (Corley *et al.*, 2001). In 2009, Epstein and Hamric introduced the concepts of moral residue and the crescendo effect, highlighting how MD can accumulate over repeated events, emphasising its lasting impact beyond individual episodes (Epstein and Hamric, 2009). More recently, the related concept of moral injury has entered healthcare discourse, describing the deeper psychological, emotional, and spiritual harm that can occur when severe or repeated

MD remains unresolved and begins to undermine an individual's moral integrity or sense of self (Litz *et al.*, 2009; Dean, Talbot and Dean, 2019).

Since the mid-2010s, scholars have increasingly critiqued Jameton's original, narrowly framed definition of moral distress (MD), which centred on experiences of moral constraint and was developed primarily within nursing contexts. More recent work argues that MD can affect a broad range of HCPs, arises across diverse morally challenging situations, and does not necessarily require the presence of constraint to be experienced. Fourie (2015) advocated for broadening of the definition, recognising MD as a specific psychological response to various kinds of morally challenging situations, while Morley *et al.* (2019) also proposed broader definitions and taxonomies encompassing moral constraint, conflict, and uncertainty. These authors suggest that MD arises when three conditions are met: a moral event occurs, psychological distress results, and there is a direct causal link between the two. In practice, MD commonly manifests as feelings of frustration, guilt, anger, grief, helplessness, powerlessness, or shame when professionals are unable to provide the amount, type, or quality of care they feel patients need or deserve (McCarthy and Deady, 2008). In this research, MD is understood in its broader sense as arising when HCPs experience conflict between their personal or professional values and the realities of care delivery and feel constrained or unable to act in accordance with their moral judgement, resulting in emotional and psychological distress.

Measurement of moral distress (MD) has likewise evolved from the original Moral Distress Scale (Corley *et al.*, 2001), developed for ICU nurses, to the Moral Distress Scale - Revised (Hamric, 2012), and most recently the Measure of Moral Distress for Healthcare Professionals (MMD-HP**)** (Epstein *et al.*, 2019), designed for use across disciplines and care settings. It is now widely recognised that MD affects a broad range of HCPs and should be understood as a phenomenon that transcends disciplinary boundaries. Reflecting this growing awareness, several assessment tools have been developed in recent years, including the the Moral Distress Thermometer (Wocial and Weaver, 2013), the Moral Distress Risk Scale (Schaefer, Zoboli and Vieira, 2019) and the Moral Distress Questionnaire (Eizenberg, Desivilya and Hirschfeld, 2009), each designed to capture experiences of MD across different

professional groups (Rivard and Brown, 2019; Guariglia *et al.*, 2023; Latimer *et al.*, 2023; Boulton and Farquharson, 2024; Jeong *et al.*, 2024).

Despite considerable progress, ambiguity surrounding the definition of MD persists (Morley *et al.*, 2019; Deschenes *et al.*, 2020), and debate continues over the most appropriate methods for its measurement (Tian *et al.*, 2021; Kolbe and De Melo-Martin, 2023). This reflects the inherent complexity of a construct shaped by multiple antecedents that differ across professional groups and clinical settings, fluctuate over time, and are influenced by individual characteristics (Kolbe and De Melo-Martin, 2023). The diversity in definitions, context-specific triggers, temporal variability, and reliance on heterogeneous self-report measures further complicates reliable measurement and cross-study comparison (Houle *et al.*, 2024). Nevertheless, a consistent theme in the literature emphasises the importance of distinguishing MD from general psychological or emotional distress, in order to preserve the ethical significance and conceptual integrity of the term, MD arises specifically from a conflict in values between the care the professional strives to deliver and what they feel able to do in practice (Lamiani, Borghi and Argentero, 2017).

MD has been most extensively studied in critical care and ICU, palliative care and oncology, and emergency departments, with a pronounced surge during the COVID-19 pandemic (Figure 1.1) (Sandberg *et al.*, 2021; Guariglia *et al.*, 2023; Latimer *et al.*, 2023; Boulton and Farquharson, 2024).

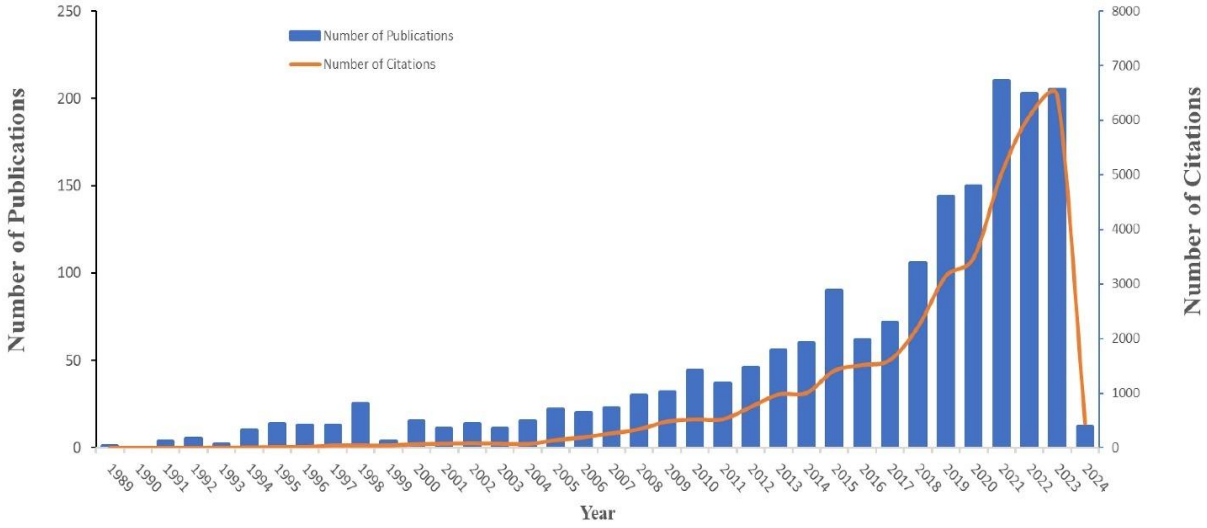


**Figure 1.1:** Trends in Annual Publications and Citations on Nurses' Moral Distress Worldwide From 1989 to 2024. Published in (Li et al., 2024, p.3).

Since then, interest has expanded into areas such as community care (Giannetta *et al.*, 2021), residential and long-term care (Vinckers and Landeweer, 2025), mental health (Lamoureux, Mitchell and Forster, 2024), and neonatal services (Sakai *et al.*, 2025). The focus on moral agency and ethical dissonance is especially salient in professions grounded in care, justice, and human dignity, making MD a critical lens through which to examine the moral and emotional burdens faced by practitioners working in ethically complex environments (Aghakhani *et al.*, 2025).

Ethical principles such as autonomy, beneficence, non-maleficence, and justice provide the foundation for professional conduct in healthcare, guiding clinicians to respect patients' choices, promote well-being, minimise harm, and ensure fairness in the allocation of care (Varkey, 2021). In practice, however, these principles frequently come into tension, particularly in complex care environments shaped by organisational constraints, resource limitations, and policy directives. For example, tensions may arise between autonomy and beneficence when a patient refuses an intervention that clinicians believe would improve comfort or safety. Similarly, conflicts between beneficence and non-maleficence can emerge when a proposed intervention offers potential benefit but also carries a significant risk of distress or loss of dignity. Challenges to justice are evident when clinicians seek to provide intensive, individualised care but face system-level limitations in time, staffing, or

resources that restrict what can realistically be offered (Akdeniz, Yardımcı and Kavukcu, 2021; Alanazi *et al.*, 2024). Together, these tensions illustrate how ethical principles, while foundational, are often difficult to uphold simultaneously in practice, particularly in settings characterised by progressive illness and end-of-life care (Finlay, 2022).

It is within these ethically complex contexts that MD can arise, when HCPs recognise the ethically appropriate course of action, experience ethical tension, or feel uncertain about the best ethical path forward, yet perceive themselves as unable to act in accordance with their moral judgement (Jameton, 1984; Fourie, 2015). MD therefore reflects not a lack of ethical awareness, but the emotional and psychological impact of being constrained from enacting deeply held professional and moral values (Epstein and Hamric, 2009; Morley, Bradbury-Jones and Ives, 2022). One of the most frequently cited triggers of MD in the literature is the perception of poor-quality patient care (Meltzer and Huckabay, 2004; Hamric and Blackhall, 2007). HCPs often experience MD when they witness, or are required to participate in care they perceive as inadequate, particularly in high-stakes situations such as end-of-life care or decisions regarding life-sustaining treatments. This distress may be further intensified when patients' wishes are unclear or when there are concerns about their quality of life. Moreover, MD can be exacerbated when clinicians witness prolonged patient suffering that they feel unable to alleviate because of clinical limitations, policy constraints, or shortages in resources (Lamiani, Borghi and Argentero, 2017).

MND is a terminal condition with very limited treatment options, placing HCPs in care situations that are inherently emotionally and ethically demanding. Although the literature has long recognised the emotional and ethical complexity of caring for people and families living with MND (Carey, 1986; Connolly, Galvin and Hardiman, 2015; Phelps *et al.*, 2022; Artioli *et al.*, 2025), MD and its specific contributors in this workforce remain underexplored. As Gula et al. (2024) highlight, terminal neurological conditions inherently impose significant ethical challenges from the point of diagnosis. These illnesses are often difficult to diagnose, may involve altered cognition, and are frequently complicated by prognostic uncertainty. These factors

fundamentally affect how individuals engage with care and can create persistent ethical tensions for those delivering it.

Given that MD is dynamic and context-dependent, it is essential to identify contributors that are specific to particular settings and professional roles. A recent systematic review by Schofield *et al.* (2021) highlighted that the range of ethical challenges faced by specialist palliative care practitioners often exceeds those described in textbooks and standard ethics resources. Many of these challenges were found to be highly context-specific, reflecting the complexity of real-world practice and limiting the extent to which they can be readily generalised across settings. This underscores the importance of understanding the experiences of HCPs involved in MND care, including the unique challenges they face and the situations they perceive as most distressing in this work. Such insight may enable the development of targeted interventions that respond to real-world clinical scenarios, ethical dilemmas, and structural constraints that generate MD and its associated psychological strain (Currie and Laing, 2023).

MD has garnered increasing attention in occupational well-being research due to its consistent association with burnout, compassion fatigue, and intention to leave the profession across diverse healthcare settings (Allen *et al.*, 2013; Whitehead *et al.*, 2015; Lamiani, Borghi and Argentero, 2017; Colville *et al.*, 2019). While burnout and compassion fatigue are well-established concepts within the HCP well-being literature (1.2.1 Burnout; 1.2.2 Compassion Fatigue), they do not fully capture the moral and ethical dimensions inherent in healthcare work. Although distinct in their origins and manifestations, MD, compassion fatigue, and burnout converge in their detrimental effects on HCPs' well-being, quality of life, and capacity to function effectively in complex clinical environments (Maunder *et al.*, 2023). Understanding the proximal drivers of MD, and how it is experienced across specific clinical populations, therefore offers concrete opportunities for targeted prevention and mitigation (Austin, 2012; Morley, Bradbury-Jones and Ives, 2022), with the potential to positively influence broader aspects of professional well-being.

Although evidence for interventions targeting MD remains limited and no standardised framework currently exists (Amos and Epstein, 2022), recent reviews

emphasise the critical importance of organisational commitment, highlighting the need for institutions to recognise and address modifiable system-level factors that contribute to MD (Amos and Epstein, 2022). To date, most evaluated interventions focus on the team or individual level, including education, facilitated reflection, ethics consultation, and multidisciplinary ethics rounds (Amos and Epstein, 2022). While many report reductions in MD, methods vary widely across settings, and studies often rely on small convenience samples with notable design limitations (Amos & Epstein, 2022; Morley et al., 2021). Developing effective interventions for MD requires a clear, context-specific understanding of the factors that drive it within particular clinical settings (Wocial *et al.*, 2024). This is especially important in emotionally and ethically complex care environments, where the sources of MD may differ from those identified in other contexts. Accordingly, understanding the key drivers and experiences of MD among professionals working with patients and families affected by MND is a critical first step in informing meaningful and targeted support strategies.

## 1.3 The Positive Impact of Caregiving Work on Professional Well-being and Quality of Life

While most research on HCP well-being focuses on the challenges and risk factors associated with turnover and reduced professional quality of life, it is equally important to recognise the rewards inherent in healthcare work, particularly in roles that involve caring for people with complex or high-level needs (Bamforth *et al.*, 2023). Despite significant emotional and ethical challenges, many professionals, in particular those working in palliative and end-of-life care roles, have reported high levels of job satisfaction, meaning, and commitment to their work (Moreno-Milan *et al.*, 2019; Gamskjaer, Werlauff and Handberg, 2022). Most enter healthcare out of a genuine desire to help improve the lives of others, and this sense of purpose can be profoundly fulfilling (Wallis *et al.*, 2023; Chmielewska *et al.*, 2025). However, little is known about what motivates some HCPs to specialise in the care of plwMND, or

about the factors that enable them to sustain their commitment and capacity for compassionate care for these patients and families.

### 1.3.1 Compassion Satisfaction

Compassion satisfaction refers to the positive feelings and fulfilment HCPs derive from being able to help others and from doing their work well (Stamm, 2010). This can also encompass positive feelings regarding work colleagues and the experience of making valuable contributions to the work setting and to wider society (Stamm, 2010). While related to general job satisfaction, compassion satisfaction is distinct in its emphasis on the meaning-based rewards of helping others, rather than general work-related factors such as pay, workload, or professional development (Roney and Acri, 2018). It is most commonly measured using the Professional Quality of Life Scale (ProQOL-5), which measures compassion satisfaction alongside burnout and secondary traumatic stress as components of compassion fatigue (1.2.2 Compassion Fatigue) (Stamm, 2010).

Stamm (2010) emphasises that higher levels of compassion satisfaction (CS) can act as a protective or buffering factor against compassion fatigue (CF), helping individuals remain resilient in demanding professional roles. This has also been supported in a number of studies, showing an inverse relationship between CS and CF (Baqeas, Davis and Copnell, 2021; Ali, Mohamed and Saber, 2022). However, Stamm (2010) also highlights that CS and CF are not simply opposite ends of a single continuum, but often coexist, meaning a person may experience deep fulfillment from their work while simultaneously being at risk for emotional exhaustion or trauma-related stress (Stamm, 2010). According to Stamm (2010), factors within the work, client, and personal environments can influence both CS and CF, suggesting that fostering compassion satisfaction and managing work-related fatigue are equally important for sustaining a healthy professional quality of life (Stamm, 2010).

The majority of research on moral distress (MD) has also focused on its negative impact on professional quality of life and its associations with compassion fatigue;

however, few studies have also highlighted the potential for positive outcomes. When MD is successfully addressed or managed, it can lead to personal and professional growth, or even a sense of professional fulfillment from overcoming a difficult situation (Hanna, 2004; Gustavsson *et al.*, 2025). While it has been suggested that CS may function as a protective factor against MD and related psychological strain, evidence for this is still emerging. Dodek *et al.*, (2021) and Gustavsson *et al.* (2025) both found that CS was weakly associated with reduced MD among critical care professionals, and among professionals during the COVID-19 pandemic.

Although the professional benefits of working with patients and families living with MND are still underexplored in the literature, emerging qualitative evidence has indicated that this work can provide significant professional meaning and fulfilment. Gamskjaer, Werlauff and Handberg (2022), found that professionals working with MND patients in Denmark demonstrated a fundamental drive for this work, grounded in a strong sense of purpose and meaningful contribution. While Hansen, Burton-MacLeod and Schellenberg (2024), found that MND specialists experienced personal satisfaction, from being able to provide tangible solutions and from '*doing their best for patients'*. However, compassion satisfaction and its potential contributing factors have received little attention within the context of MND care. Understanding whether compassion satisfaction is relevant across the MND workforce and identifying the mechanisms that foster meaning and fulfilment in this work, is crucial. These factors may strengthen resilience, reduce burnout and turnover intentions, and ultimately enhance workforce sustainability within this small, highly skilled professional community. Moreover, experiences of professional fulfilment and a sense of making meaningful contributions to patient and family care may act as protective factors, buffering against moral distress and other forms of psychological strain. This research will explore these relationships to better understand how compassion satisfaction may contribute to professional resilience and psychological well-being within the MND workforce.

### 1.3.2 Resilience and Coping

Resilience and coping are central to sustaining HCPs in high-stress environments and mitigating the risk of burnout and other forms of occupational and psychological strain (McCain *et al.*, 2018; Maresca *et al.*, 2022; Guraya *et al.*, 2025). Although closely related, the two are conceptually distinct. Coping refers to the strategies individuals use to manage stress in the moment (Maresca *et al.*, 2022), whereas resilience represents the broader, long-term capacity to adapt and maintain well-being in the face of sustained adversity (Sheikhrabori, Peyrovi and Khankeh, 2022). Adaptive coping strategies, such as problem-solving, seeking support, and cognitive reframing, can strengthen resilience over time (Bondarchuk *et al.*, 2024), while resilient individuals are typically more adept at selecting and applying effective coping strategies, creating a reciprocal relationship that supports sustained functioning under pressure (Sheikhrabori, Peyrovi and Khankeh, 2022).

Among the various frameworks for understanding coping, the most longstanding and widely applied framework is Lazarus and Folkman's Transactional Model of Stress and Coping, which conceptualises coping as a dynamic process involving primary appraisal of a stressor and secondary appraisal of available resources (Lazarus and Folkman, 1984). Problem-focused coping involves actively addressing the source of stress, whereas emotion-focused coping aims to regulate the emotional response without directly changing the situation (Lazarus and Folkman, 1984; Indunil Karunarathna *et al.*, 2024). Evidence suggests that avoidance and other emotion-focused strategies are associated with higher burnout, while active, problem-focused coping is linked to greater resilience and reduced distress (Shin *et al.*, 2014; McFadden *et al.*, 2021). However, the effectiveness of these strategies is context-dependent; problem-focused coping tends to be beneficial when individuals can exert control over stressors, whereas emotion-focused strategies, such as seeking social support, cognitive reappraisal, or spiritual engagement, may be protective when stressors are uncontrollable or enduring (Shin *et al.*, 2014; Indunil Karunarathna *et al.*, 2024).

For HCPs working with individuals and families affected by MND, the progressive and terminal nature of the illness, coupled with the emotional complexity of ongoing loss

and limited treatment options has the potential to create unique challenges that lie beyond the clinicians' control. In this context, adaptive emotion-focused coping, such as team-based support and reflective practice, may be especially important for sustaining resilience. However, how professionals cope with and manage the demands of MND patient care has not been widely reported in the available literature.

A systematic review by Zanatta, Maffoni and Giardini (2020) examined resilience among palliative HCPs and found that resilience plays a significant protective role in managing the emotional and psychological demands of end-of-life care. The review identified resilience as a dynamic process rather than a fixed trait, influencing how professionals adapt to stressors such as repeated exposure to death, ethical dilemmas, and patient suffering. Higher levels of resilience were consistently associated with lower burnout, reduced secondary traumatic stress, and death anxiety, as well as positive outcomes including compassion satisfaction, hope, perspective-taking, and post-traumatic growth. However, the authors noted that the evidence base remains limited, with few quantitative studies, small sample sizes, and a lack of robust intervention research. They concluded that resilience may act as a key modulating factor in determining whether palliative care work leads to psychological distress or positive adaptation (Zanatta, Maffoni and Giardini, 2020).

Individual resilience has also been identified as playing a critical role in buffering the effects of moral distress, moral resilience is defined as the ability to sustain or restore integrity when confronted with moral complexity, confusion, distress, or setbacks (Rushton, 2017). Although resilience is associated with positive outcomes and longevity in complex clinical environments, some authors warn that an excessive focus on personal resilience risks obscuring the systemic and organisational conditions that often underpin moral distress and burnout (Tan, 2022; Xames, 2025) . Nevertheless, resilient clinicians are generally better equipped to manage these occupational stressors and maintain emotional well-being in ethically and professionally challenging situations, for example Clark *et al*. (2021) found that resilient emergency department nurses were more likely to engage constructively with workplace challenges, thereby reducing moral distress. While individual resilience cannot eliminate moral distress or the systemic and clinical conditions

that underlie it, it has been found to serve as an important protective factor, enabling professionals to cope more effectively with the emotional and moral demands of their work (Rushton, 2017). Understanding how clinicians develop and apply coping strategies and the role of resilience in MND care, and whether these factors enhance their ability to manage the demands of this work, remains an important area that will be further explored and considered in this research.

## 1.4 Intention to Leave, Turnover, Retention and Absenteeism

Turnover intention in healthcare refers to the likelihood that staff will leave their role or profession (Wynendaele *et al.*, 2025). It is a strong predictor of actual attrition and poses significant risks to organisational efficiency, as well as to the quality, safety, and continuity of patient care (Obeng and Atan, 2024). Its drivers are multifactorial, with burnout and moral stressors consistently identified as key contributors; however, variations across roles, specialties, and care settings highlight the need for context-specific understanding (Wynendaele *et al.*, 2025). Similarly, work-related absenteeism or time away from work due to illness, stress, or job-related factors, is closely linked to turnover intention (Leontaridi and Ward-Warmedinger, 2002). Both outcomes frequently arise from systemic pressures such as high workloads, inadequate staffing, moral distress, and burnout, which together can create a self-perpetuating cycle that increases strain on remaining staff (Karakachian and Colbert, 2019; Heistad *et al.*, 2022; Rhéaume, Breau and Boudreau, 2025).

For plwMND, who rely on specialist expertise for symptom management and psychosocial support across the progressive stages of illness, sustaining a skilled workforce is critical. However, as outlined above, the complex and demanding nature of MND care may place these professionals at heightened risk of moral distress, burnout, compassion fatigue, absenteeism, and turnover intention. Identifying the prevalence and underlying causes of these outcomes, as well as factors that may support and contribute to professional retention within MND services, is therefore essential for ensuring the long-term sustainability of this specialist workforce, a topic that has not yet been adequately addressed in MND workforce research.

## 1.5 National and International Occupational Health and Well-being Policy

Over recent decades, the conceptualisation of workplace well-being and occupational health, particularly within healthcare settings, has undergone significant cultural and structural transformation (Kirsten, 2024). Early occupational health policies and initiatives primarily focused on the prevention of physical injury and workplace hazards, reflecting a risk-oriented and compliance-based approach (Kirsten, 2024). In contrast, contemporary policy and research increasingly recognise the centrality of psychological well-being, resilience, work–life balance, and supportive organisational cultures as fundamental determinants of workforce sustainability, quality of care, and patient safety (Sonnentag, Tay and Nesher Shoshan, 2023; Hoxha *et al.*, 2024; Kirsten, 2024). Within the Irish context, this evolution is exemplified by the *Healthy Ireland at Work Framework (2021–2025)*, which is the first comprehensive, cross-sectoral policy dedicated exclusively to workplace health and well-being. The framework advocates a proactive and holistic strategy that integrates leadership development, organisational culture, mental health promotion, and evidence-informed practices to foster sustainable well-being across the workforce. Complementing this, the *Code of Practice on the Right to Disconnect* (2021) formalised employees' entitlement to disengage from work outside contracted hours, thereby promoting work–life balance and mitigating risks associated with digital overload and burnout.

Comparable policy and practice developments are evident across Europe and globally and relate more specifically to the challenges faced by those working in healthcare environments. Key European and global policy frameworks increasingly emphasise the well-being of HCPs as fundamental to sustainable and resilient healthcare systems. The World Health Organisation (WHO) European Region's (2023) *Framework for Action on the Health and Care Workforce 2023–2030* underscores cross-professional well-being, workforce retention, and system resilience as strategic priorities, positioning investment in health and care workers as essential

infrastructure for sustainable and effective service delivery. It advocates for comprehensive strategies that integrate mental health promotion, workforce planning, safe and supportive working conditions, and ongoing professional development across all roles and sectors. Similarly, the *WHO Global Working for Health Action Plan 2022–2030* reinforces the need for safe, healthy, and supportive work environments, recognising the central role of HCP well-being in ensuring sustainable patient care. The plan emphasises proactive measures to prevent burnout, address occupational stress, and strengthen workforce retention, positioning the protection, support, and development of the health and care workforce as a global health priority.

These policy frameworks highlight an evolving recognition of HCP well-being as a central determinant of sustainable healthcare systems and the delivery of high-quality patient care. This imperative has been further accentuated by the COVID-19 pandemic, which exposed and exacerbated vulnerabilities in the healthcare workforce well-being across many clinical settings (Kirsten, 2024). While these policies and frameworks provide a valuable foundation for promoting occupational health and well-being in healthcare, their success ultimately depends on a nuanced understanding of how HCPs experience and navigate the demands of their work within specific organisational, professional and cultural contexts. Consequently, context-sensitive inquiry is essential to ensure that interventions and strategies are effectively tailored to the unique characteristics, pressures, and needs of diverse healthcare populations and settings, thereby enhancing their relevance, adoption, and long-term impact. Research on the MND workforce is particularly important, given the demanding nature of MND care and the paucity of research addressing the experiences, challenges, and well-being of these HCPs.

## 1.6 Chapter One Summary

MND presents a complex neurodegenerative condition that imposes profound physical, psychological, and social burdens on both those affected and their families. It is often described as one of the most devastating adult-onset conditions,

characterised by progressive and cumulative loss, culminating in total dependence and ultimate death, often within a relatively short period of time.

Despite the limited availability of curative or reversible treatment options, HCPs play a pivotal role in the provision of compassionate, and supportive care, focused on managing the multitude of associated symptoms and optimising quality of life for those affected. In order to sustain HCPs ability to provide consistent and compassionate care, throughout the patients disease journey, we need to understand the most pressing challenges facing those working with these patients and their families, and how both the practical and psychological challenges of supporting patients and families facing one of the most fatal and debilitating conditions of adult life, can affect the emotional and psychological well-being of those who responsible for their care.

Although theoretical and empirical frameworks exist to identify, manage, and mitigate risks to HCP well-being in high-stress clinical environments, such as moral distress, compassion fatigue, and burnout, their application and relevance within the context of MND care remain underexplored. The expectation that HCPs can engage repeatedly in emotionally charged and ethically complex care situations without being affected is largely unrealistic. Accordingly, investigation is warranted to better understand the pressing stressors and challenges they face, and to identify how best to support them in providing safe and effective care while also safeguarding their own personal and professional well-being.

The next chapter will present the overall aim and objectives of this research and the methodological approach that will be used to achieve these. Chapter Three further establishes the context and direction for this research and presents the findings of a scoping review exploring HCPs' experiences of working with patients and families affected by MND, as well as the impact of this work on their emotional and psychological well-being.

# Chapter 2: Methodology

## 2.1 Introduction

This chapter sets out the methodological approach used in this PhD. It begins by presenting the research aims and providing an overview of the study design. The philosophical assumptions underpinning the research are discussed followed by a justification for the chosen research design: an exploratory sequential mixed methods design. This design incorporates four distinct but interconnected phases, with each phase representing a separate study that contributes to addressing the overall research aims. Specific details of the research methods used within each phase are presented in Chapters 3 – 6. The rationale for method selection, sampling strategies, data collection procedures, ethical considerations, and approaches to data analysis are outlined within the respective chapters.

## 2.2. Research Aim

This thesis aims to provide a comprehensive and in-depth understanding of the experiences of HCPs working with MND, explore how these experiences impact their personal and professional well-being, and inform practical recommendations for professional support and workforce sustainability.

The following objectives will support the achievement of this aim:

- To describe the experience of professional caregiving for MND from the perspective of the HCPs involved
- To explore the personal and professional challenges and rewards perceived by professionals working with MND
- To explore the positive and negative impact of working with MND on the emotional and psychological well-being of the professionals supporting them

- To identify potentially protective factors, skills, attributes, and targeted supports that may strengthen professional sustainability and retention within MND care services

## 2. 3 Research Paradigm

Pragmatism is the research paradigm underpinning this PhD. This paradigm views qualitative and quantitative research methods as complementary rather than conflicting, ways of generating knowledge (Maarouf, 2019). Historically the quantitative and qualitative paradigms faced one another in a long-lasting debate or what was known as "*the paradigm war*", a debate that started in the '70s and continued through the '80s and the '90s (Smith, 1983; Sale, Lohfeld and Brazil, 2002; Hall, 2013). During this time groups of researchers, often referred to as *"purists"*, argued for the superiority of their preferred approach and were adamant that quantitative and qualitative approaches could not be combined because of paradigmatic differences, an argument known as the "*incompatibility thesis*" (Fetters, Curry and Creswell, 2013; Morgan, 2014). Since the 1990's new approaches of mixing quantitative and qualitative research methods have emerged and increased in popularity (Johnson and Onwuegbuzie, 2004; Teddlie and Tashakkori, 2006, 2012; Glogowska, 2011; Biddle and Schafft, 2015) particularly in the health and social science fields (Tariq and Woodman, 2013; Wasti *et al.*, 2022).

Pragmatism focuses on addressing real-world problems and the practical consequences of research. The research question is placed at the centre of methodological decision-making and facilitates flexibility in choosing methods based on what best addresses the issue at hand (Creswell, 2014; Shannon-Baker, 2016). Both subjective and objective forms of knowledge are valued, recognising that interpretivist (qualitative) and positivist (quantitative) perspectives offer complementary insights and together contribute to a more holistic understanding of complex research problems (Creswell, 2014; Shannon-Baker, 2016). As in this PhD, a pragmatic approach is particularly valuable when investigating complex, real-world issues, where both personal experiences and measurable outcomes are important for understanding "*what happens*" and "*what works*" in practice (Maarouf, 2019; Gillespie, Glăveanu and De Saint Laurent, 2024). Accordingly, the research aim of

this PhD is best addressed through the combined use of quantitative and qualitative methods, with the integration of findings across approaches.

## 2.4 The use of Mixed-Methods Research

Mixed-methods research is defined by Johnson et al. (2007) as:

> *'The type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration'* (Johnson et al., 2007, *p.123)*.

A key distinguishing feature of mixed-methods research, as opposed to multi-methods research, is the deliberate integration of methods and findings at various stages of the research process, resulting in a synthesised outcome that offers deeper insights than any single phase could provide on its own (Fetters, Curry and Creswell, 2013). While no single, universally adopted reporting guideline or quality framework exists for mixed-methods research, several initial attempts have been made and a number of key quality indicators identified (Guetterman, Molina-Azorin and Fàbregues, 2023).

These key quality indicators include a clearly articulated rationale for adopting a mixed-methods approach; the rigorous design and implementation of both quantitative and qualitative components; a strong alignment between the chosen methods and the research questions and a clear explanation and justification of the specific mixed-methods design employed (e.g., explanatory, sequential, embedded). Crucially, genuine integration of methods and findings throughout the research process is essential, yet this is frequently the most poorly executed and criticised aspect of mixed-methods research (Bazeley, 2024; Skamagki *et al.*, 2024).

Each of these quality indicators have been addressed in this PhD research and are outlined below:

### Explicit rationale for selecting a mixed-methods approach

As limited prior research has examined the workforce experiences of professionals working with MND, a mixed-methods design was selected to support both exploratory and explanatory aims and to capture the complex and multifaceted nature of working with MND. An initial exploratory scoping review was undertaken to map existing knowledge of professionals' experiences in this field. This informed a subsequent in-depth qualitative phase, which explored the key challenges encountered by, and perspectives of, professionals working with plwMND. In order to further determine the impact of this work on professional well-being, insights gained from these phases, were used to design and develop a meaningful and contextually relevant cross-sectional online survey, that measured important aspects of professional well-being and quality of life, relevant to working with his patient population. The subsequent use of quantitative methods facilitated wider engagement with professionals, allowing for validation and expansion of earlier findings and the identification of significant patterns in the data. The integration of these complementary methods supported a more comprehensive understanding of the research problem and supported the overarching aim of generating practical, evidence-based solutions and recommendations that could be considered and applied in everyday practice. This approach also ensured that the resulting recommendations were not only evidence-based but also practically applicable and grounded in the realities of professional practice.

### Rigorous design, justification and execution of qualitative and quantitative components

Each of the four phases of this research followed rigorously applied methodologies and methods that were selected for their appropriateness in addressing the specific aims and objectives of each study. Details of the methodologies employed and the justification for their use are outlined at the beginning of the respective chapters: Scoping Review (Chapter 3), Qualitative Focus Group Study (Chapter 4), Cross-sectional Online Survey (Chapter 5), and Extended Pillar Integration Process (Chapter 6). The methodologies were applied consistently throughout each phase and are reported in accordance with the relevant reporting guidelines, including the PRISMA-

ScR (Tricco *et al.*, 2018) (Appendix C), Reflexive Thematic Analysis Reporting Guideline (RTARG) (Braun and Clarke, 2024) (Appendix I), and Consensus- Based Checklist for Reporting of Survey Studies (CROSS) (Sharma *et al.*, 2021) (Appendix Q).

### Clear articulation and justification of the specific mixed-methods design used

In response to frequent criticism of inadequate justification for methodology, study design, and the integration of methods in mixed-methods research (Bazeley, 2024; Skamagki *et al.*, 2024), several theorists have developed mixed-method typologies, or approaches, providing the theory and processes to guide researchers in designing and integrating multiple strands of inquiry (Greene and Caracelli, 1997; Morgan, 1998; Creswell, 2003; Morse, 2003; Tashakkori and Teddlie, 2003; Creswell and Plano Clark 2007; Creswell, 2014)

An exploratory sequential mixed methods design was adopted for this research (Creswell, 2014). Within this approach, qualitative data are first collected and analysed, with findings subsequently informing the quantitative phase (Onwuegbuzie, Bustamante and Nelson, 2010). Two main factors informed the decision regarding the selection of an exploratory mixed-methods framework for this study: 1) the relative infancy of the literature on this topic, which necessitated an exploratory process beginning with qualitative inquiry, and 2) a desire to gain a broader understanding of the issue, engage a wider group of professionals and measure and compare professional well-being outcomes between different groups of professionals, thereby requiring a quantitative phase. The preceding phase of qualitative inquiry was essential in this study to ensure that quantitative data collection was firmly grounded in the real-world experiences of professionals working with MND. This sequential design strengthened the study's capacity to produce findings that are both methodologically robust and practically meaningful for clinical and professional practice.

### Genuine integration of methods and findings throughout the research process

Fetters, Curry and Creswell (2013) outline how integration in mixed methods research can be achieved at the design, methods, interpretation, and reporting stages. Although detailed guidance on achieving integration has been provided by several scholars (O'Cathain, Murphy and Nicholl, 2010; Fetters, Curry and Creswell, 2013; Johnson, Grove and Clarke, 2019), there is still common criticism that many studies fail to effectively combine their qualitative and quantitative components.

Integration in this study occurred at a number of different stages throughout data collection, analysis, reporting and interpretation.

1) First, a scoping literature review was conducted to identify existing evidence and knowledge gaps. The questions arising from this review informed the study design, recruitment strategy, and development of the qualitative focus group topic guide, which was used to explore these initial issues in greater depth.
2) Second, the qualitative analysis of focus group data directly informed the design of the cross-sectional survey. It guided the design of relevant questions, section of outcome measures and supported the development of targeted statements aimed at identifying factors that may contribute to moral distress specific to working with an MND population.
3) The cross-sectional survey collected quantitative data but also incorporated open-text or qualitative responses to deepen understanding of the results and to further expand on some of the qualitative findings from Phase Two (qualitative focus group study), with a broader group of professionals. The quantitative and qualitative data from this study were also analysed and reported simultaneously.
4) Finally, integration culminated in Chapter 6 of this thesis, where findings from all phases ware integrated using the Extended Pillar Integration Process (ePIP) and practical, evidence informed recommendations were developed to highlight the specific support needs of professionals working in this demanding area of clinical practice.

### 2.4.1 Reflection on Using a Mixed Methods Approach

Using a mixed methods approach in this research offered a more comprehensive understanding of the topic than either method could have achieved alone. Relying solely on qualitative methods would have limited the applicability of findings to a small cohort of Irish HCPs, while the exclusive use of quantitative methods risked producing a survey instrument shaped predominantly by the researcher's assumptions, rather than being grounded in the experiences of those working in the field. Using both methods, in an integrated way, enabled the researcher to generate practical results, with direct relevance and applicability to everyday clinical practice. However, this approach did pose several challenges, particularly the complexity involved in designing and executing the study, which required a novice researcher to develop proficiency in both qualitative and quantitative data collection and analysis skills. Additionally, integrating two distinct data types drawn from similar, yet slightly different samples proved challenging. Despite these challenges, the use of a mixed methods approach was the optimal method to address the aim of this research and provided a valuable opportunity for the researcher to develop skills in both qualitative and quantitative inquiry, while also fostering critical thinking and analytical abilities during the integration and synthesis phases.

## 2.5 Outline of the Study

This study follows an exploratory sequential mixed-methods research design. It was conducted across four distinct yet interlinked phases, each designed to address the overall research aim (Figure 2.1).

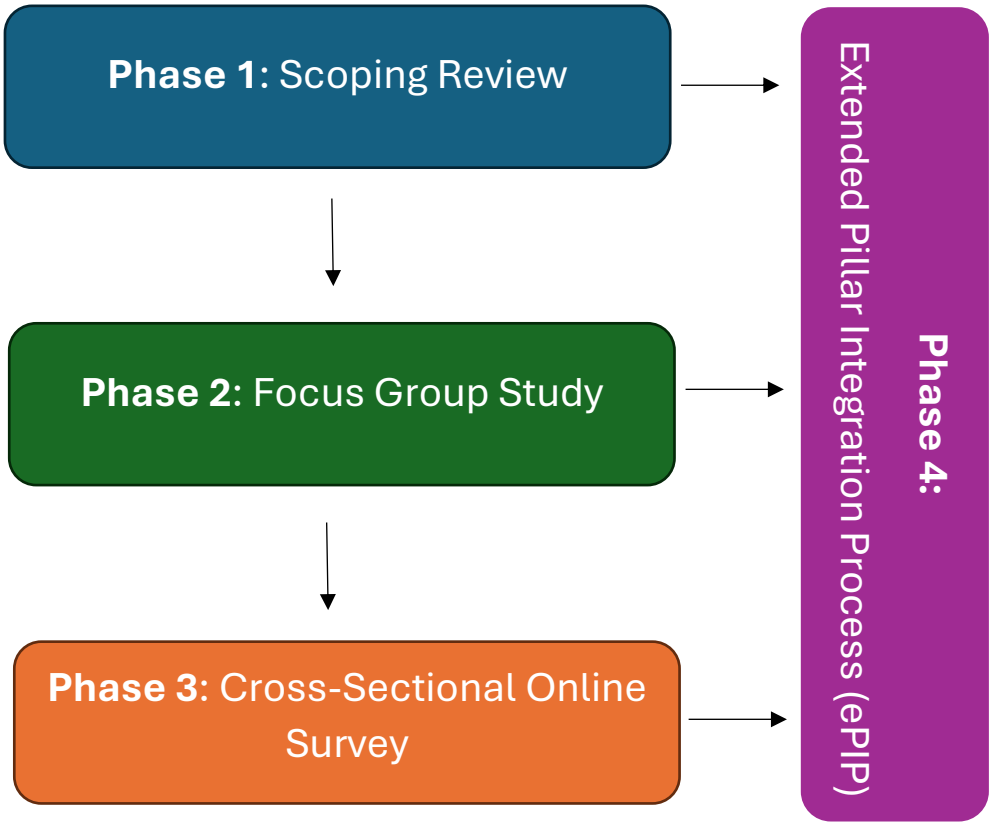


**Figure 2.1:** Flow Diagram of the Research Design and Phases

- Phase One involved a scoping literature review, conducted to map existing evidence on HCPs' experiences of working with patients and families living with MND, as well as the emotional and psychological impact of this work (see Chapter 3). This phase also identified gaps in knowledge, which informed the focus and direction of subsequent phases.
- Phase Two was a qualitative focus group study, which built upon the findings and gaps identified in Phase One (see Chapter 4). This study explored the shared experiences of HCPs from various disciplines and services involved in providing care for MND patients and their families in Ireland. Reflexive thematic analysis was applied to explicate common stressors, challenges, rewards, and perceived supportive or protective factors experienced by professionals working with this population.
- Phase Three consisted of an international survey of HCPs working in services for individuals living with MND across Europe (see Chapter 5). This study

measured key aspects of HCP well-being relevant to working with an MND population, including moral distress, professional quality of life, and resilient coping. It also addressed issues such as absenteeism, workforce retention, and additional factors perceived as helpful in supporting this workforce.

- Phase Four involved an integration phase, where the Extended Pillar Integration Process was used as a formal and structured approach to integrate findings from the preceding three phases of inquiry (see Chapter 6). The overall findings were synthesised, and practical recommendations for both practice and policy are provided.

The following four chapters outline the four distinct phases of this research, with the specific methodologies and methods employed in each phase described in detail within the respective chapter.

# Chapter 3: Phase One – Scoping Review

## Working With People Living with Motor Neurone Disease and The Impact on Professionals' Emotional and Psychological Well-Being: A Scoping Review

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**Author Contributions:** **MW developed the study protocol, completed the search process, extracted and analysed data and wrote the report/manuscript**. AC reviewed the study protocol, assisted with the search process, reviewed, edited and approved the final version of the report/manuscript. DM developed the search strategy and assisted with the search process. MG reviewed the study protocol, assisted with the search process, reviewed, edited and approved the final version of the report/manuscript.

## Abstract

**Background:** Integrated multidisciplinary care is required to manage the progressive and debilitating symptoms associated with motor neurone disease. Providing the level of care required by this population can be both clinically and emotionally challenging. To support those working with these patients it is important to understand the experience of the entire multidisciplinary team involved and the impact of working with motor neurone disease on their emotional and psychological well-being.

**Aim:** To identify what is known about (1) healthcare professionals' experience of working with motor neurone disease and (2) the impact of this work on their emotional and psychological well-being.

**Design**: Scoping review. Review protocol registered on Open Science Framework.

**Sources**: Five electronic databases were searched in January 2023 and 2024. Grey literature and hand searches were completed.

**Results**: Fifty-one sources published between 1990 and 2023 were included. A total of 1692 healthcare professionals are represented. Three main categories were identified: (1) The demands of providing motor neurone disease care (2) Factors influencing professionals' ability to provide desired levels of care and (3) The emotional impact of working with motor neurone disease. Subcategories are depicted within these.

**Conclusion:** Positive experiences included job satisfaction, enhanced perspective and receiving gratitude, while negative implications such as stress, emotional exhaustion and burnout also featured. The demands of motor neurone disease patient care, the organisation of services and resources required to meet patient and family needs and the emotional burden for professionals involved, warrant greater recognition in clinical practice, guidelines and future research.

## 3.1 Introduction

Much of the research on the delivery of multidisciplinary MND care has focused on the views, experiences and needs of patients and informal caregivers' (O'Brien *et al.*, 2011; Foley, Timonen and Hardiman, 2012; Oh and Kim, 2017). Patients and informal carers recognise and value high quality MDT care (Brewah *et al.*, 2022), however, they have experienced services as being fragmented (Aoun *et al.*, 2012), encountered healthcare providers with limited knowledge and understanding of MND symptoms (Hughes *et al.*, 2005; O'Brien *et al.*, 2011), received poorly communicated and conflicting information (Aoun *et al.*, 2018) and experienced difficulty accessing home care, respite, palliative care and specialist services (O'Brien *et al.*, 2011; Foley, Timonen and Hardiman, 2012; Mc Veigh *et al.*, 2019). As the disease progresses, increasing dependency and care needs have been closely associated with heightened caregiver burden (Galvin *et al.*, 2016), emotional distress (Pinto *et al.*, 2021) and reduced psychological well-being (Schischlevskij *et al.*, 2021). The significant physical and emotional strain experienced by informal caregivers is widely acknowledged in best practice and clinical management guidelines (Andersen *et al.*, 2012; MND New Zeakand, 2022; NICE, 2016; Shoesmith *et al.*, 2020).

Informal caregivers provide most of the home-based care (O'Brien *et al.*, 2012), but depend on an integrated team of professionals for support with the patients and their own physical, psychological and social needs (Güell *et al.*, 2013; Oh and Kim, 2017). Despite the level of support and care provided by professional care teams, in often clinically and emotionally difficult circumstances, the impact of this work on the their own well-being has not been widely considered in research to date (Harris *et al.*, 2018). The New Zealand best practice recommendations are the only guideline briefly referencing the clinical and emotional challenges faced by HCPs (MND New Zealand, 2022). To augment our understanding of the challenges to providing effective multidisciplinary care, that meets the needs and expectations of patients and their informal support network, it is important to consider the experiences and perspectives of the professional care providers. Some studies have addressed the challenges of professional caregiving for specific groups of professionals such as doctors (Bromberg, Schenkenberg and Brownell, 2011), nurses (Cutler, 2009;

Daneau *et al.*, 2023) or primary care teams (Lerum, Solbraekke and Frich, 2017) and in specific circumstances such as supporting the withdrawal of non-invasive ventilation (Faull, Haynes and Oliver, 2013) or communicating the diagnosis (Aoun *et al.*, 2018). However, this research has not been systematically reviewed to date.

This scoping review aims to identify healthcare professionals' experiences of working with this complex and progressive condition and determine what is currently known about the impact of working with MND on the emotional and psychological well-being of all healthcare professionals involved. This review also aims to identify areas for important future research on this topic.

## Rationale for Scoping Review

A scoping review methodology is used to identify and map available literature on a broad or emerging topic (Peters *et al.*, 2021). Scoping reviews draw on a wide variety of study designs and incorporate a broad breadth of evidence (Peters *et al.*, 2021), adopting a more flexible approach to data synthesis than systematic reviews, which typically focus on the critical appraisal of clinical outcomes and answering narrowly defined clinical questions (Munn *et al.*, 2018). A scoping review was an appropriate method for this study, as the research question is exploratory in nature and the area of interest is expansive and has not been comprehensively reviewed to date (Mak and Thomas, 2022). In addition, this approach supports an examination of how knowledge in this area has previously been generated and facilitates the identification of gaps to inform the development of future research questions (Peters *et al.*, 2021).

Arksey and O'Malley (2005), provided the foundational framework, in their seminal paper for the conduct of scoping literature reviews. They outlined a six-stage iterative process; (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting results and (6) consultation with stakeholders (an optional step). Levac et al. (2010) expanded on each stage of this framework, and in 2015 The Joanna Briggs Institute

(JBI) published a comprehensive and formal guidance document to further guide researchers following this process (The Joanna Briggs Institute, 2015). The transparent and systematic process is a particular strength of the scoping review methodology, in comparison to other less structured literature review methods (Munn *et al.*, 2018). This review followed guidance from Arksey and O'Malley (2005), Levac et al. (2010), and The Joanna Briggs Institute (2015) to produce an exhaustive, reproducible and well-structured review. The review outlines the extent, range, and nature of existing evidence on HCPs' experiences of working with plwMND and the potential impact of this work on their emotional or psychological health and well-being.

## 3.2 Methods

### Review Protocol

As recommended by the JBI (The Joanna Briggs Institute, 2015; Peters *et al.*, 2022), an a priori review protocol was developed and registered on Open Science Framework (OSF) (https://osf.io/gkjme). This protocol provides the justification for the review, outlines the review questions, the selection criteria and search strategy. The protocol was followed and adhered to throughout the review process.

### 3.2.1 Search Process

#### Eligibility Criteria

The Population, Concept and Context (PCC) framework is recommended by the JBI (The Joanna Briggs Institute, 2015; Peters *et al.*, 2022), to produce a clear and meaningful review title, question and inclusion criteria. The PCC framework is widely recommended for scoping reviews as an alternative to the Population, Intervention, Comparison, and Outcomes (PICO) framework, which is more commonly applied in systematic reviews. The intervention and outcome components of PICO are of less relevance for the purpose of a scoping review (The Joanna Briggs Institute, 2015; Munn *et al.*, 2018) . The selection criteria for this study as guided by the PCC

framework are outlined in Table 3.1. These criteria were stringently applied when considering sources for inclusion in the review.

An important consideration in the review process is determining the types of sources to be included (Joanna Briggs Institute, 2015). In this review all original study designs were included. Review articles were excluded but any relevant original studies within identified reviews were included. There was no limitation placed on year of publication, but sources were limited to the English language. As English is the native language of all primary researchers, and given the timeframe and resources allocated to the review, the use of translation services was not feasible. Moreover, as the review aimed to explore HCPs' perspectives, there was a risk of inaccurate translation and potential misinterpretation of findings without access to professional translation services.

**Table 3.1**: Selection Criteria Used to Identify Sources for Inclusion in the Scoping Review

| **Population, Concept, Context** | |
|---|---|
| **Population** | Healthcare professionals (HCPs) - medical, nursing, allied health or social care professionals who provide healthcare services for people living with MND and/or their family caregivers |
| **Concept** | Healthcare professional's perception of their experience of providing care or services for people living with MND and their families and/or their perception of the impact of providing care for people with MND on their own emotional or psychological health or well-being |
| **Context** | Any healthcare setting such as, but not limited to, hospital, hospice, community, outpatient clinics, home care or residential care, that provide a public, private, or voluntary healthcare service for people living with MND and/or their family caregivers |
| **Types of Studies** | |
| **Language** | Studies published in the English language |
| **Year** | No limitation on timeframe |
| **Study Design** | All original study designs including grey literature |

### Search Strategy

The process of identifying relevant sources to include in a scoping review should be comprehensive and identify both published and unpublished (grey) literature (The

Joanna Briggs Institute, 2015). The search strategy for this study was developed with assistance from a medical librarian (DM). Two databases were initially searched (EMBASE and Medline). Keywords and index terms from this search were reviewed and used to build the search strategy across all other databases. Five electronic databases; Embase, Medline, Cinahl, PsychINFO and Web of Science were systematically searched in January 2023. This search was repeated and updated in January 2024. See Appendix A for an example of the search strategy devised. All identified citations from these searches were exported to Endnote (Clarivate, 2024), and duplicates were removed. *Open Grey*, *ProQuest Dissertations* and *Google Scholar* were also searched using combinations of the key words used in database searching, to identify relevant unpublished or grey literature. The lead researcher completed a hand search in the reference list of each source that was selected for inclusion and in each of the review articles identified during the search.

#### Source Selection

After the removal of duplicates, all remaining citations were exported to Covidence digital review management software (Veritas Health Innovation, 2024) for screening and data management. The lead reviewer (MW) screened each identified source by title and abstract. The remaining full texts were retrieved, read, and reviewed by MW. Authors were contacted for further information on sources where full texts could not be retrieved, and interlibrary loans were obtained to access full texts when required. All full texts deemed eligible for inclusion were cross-checked by the second reviewer (AC). Any disagreements were discussed and when consensus could not be reached the third reviewer (MG) was consulted (Levac, Colquhoun and O'Brien, 2010). The reasons for full text exclusion were recorded (Figure 3.1).

### 3.2.2 Data Extraction

The data extraction tool was developed at the Protocol stage and pilot tested by the research team (Appendix B) (Levac, Colquhoun and O'Brien, 2010). The lead reviewer (MW) extracted; (1) study title, (2) author(s), (3) year of publication, (4) country of publication, (5) study design, (6) number of healthcare professional

participants, (7) profession(s) of healthcare professional participants, (8) healthcare setting participants were working in, (9) experience of providing care as described by the healthcare professional, (10) any emotional or psychological response described by the HCP or potential impact on their health or well-being. 5 sources were cross-checked at random by the second reviewer to ensure accuracy.

### 3.2.3 Data Analysis and Reporting

As guided by Levac, Colquhoun and O'Brien (2010) the data were analysed using a descriptive numerical summary of source characteristics and qualitative content analytical techniques. Conventional content analysis was used to code and categorise the extracted data as they related to the review questions (Hsieh and Shannon, 2005). This is commonly perceived as the least interpretative form of qualitative analysis and thus was appropriate in producing the desired, descriptive analysis of the results (Vaismoradi, Turunen and Bondas, 2013; Cho and Lee, 2014).

Qualitative data were imported to NVivo, data management software (QSR International, 2024) for coding and categorisation. The codes were derived directly from the data and sorted into categories and sub-categories to answer the review question. Methodological rigor of included sources were not assessed, as this was not relevant to the aim or objectives of this review (Levac, Colquhoun and O'Brien, 2010). Findings are reported descriptively, with recommendations and guidance to inform further research and practice.

This review is reported in line with the recommended reporting guidelines for scoping reviews, The Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR)(Tricco *et al.*, 2018). See Appendix C for the full and completed reporting guideline.

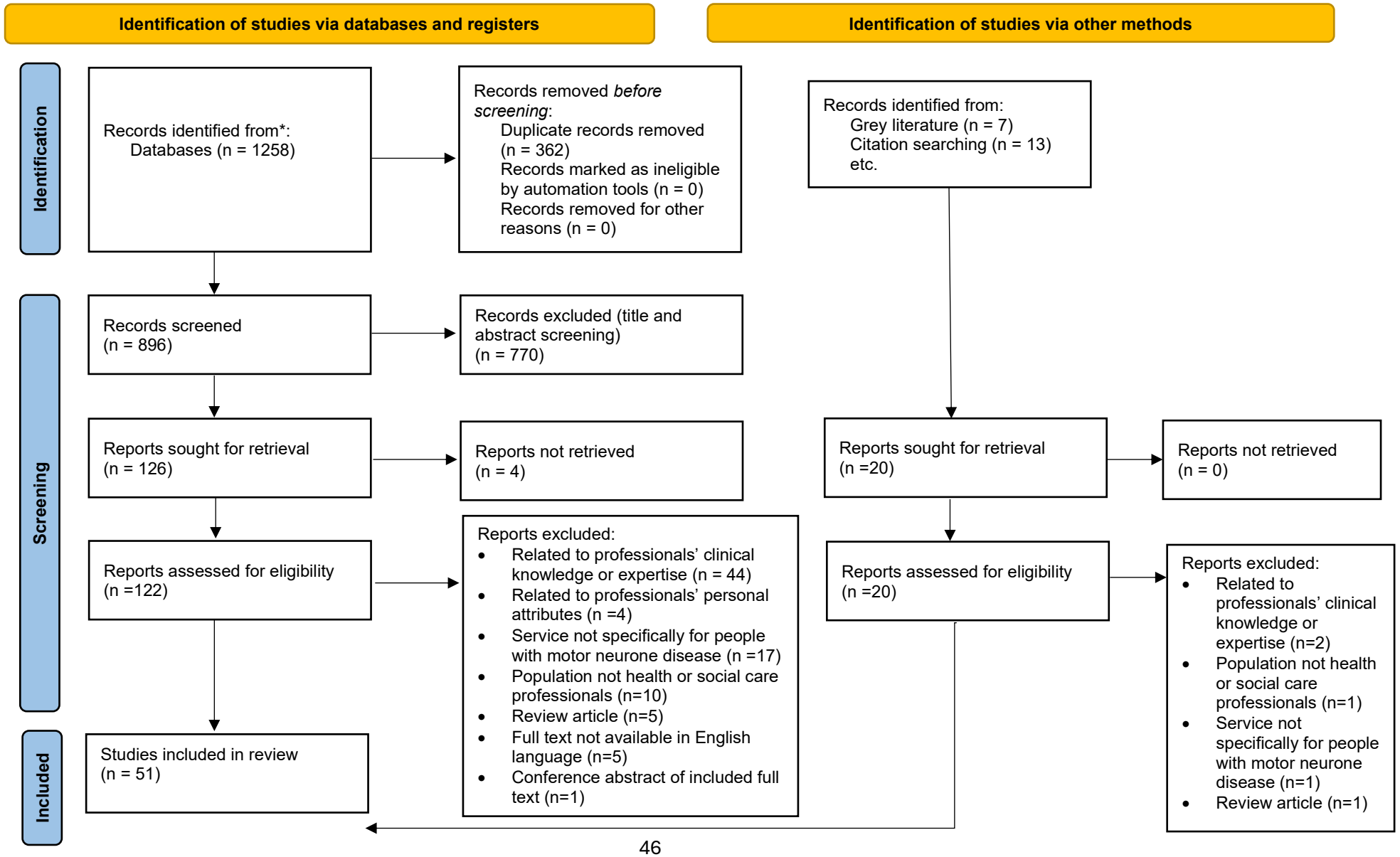
## 3.3 Results

### 3.3.1 Results of the Search Strategy and Selection Process

The PRISMA diagram, in Figure 3.1 outlines the study selection process (Page *et al.*, 2021). 1258 citations were identified from five electronic databases (January 2023 & 2024). 342 duplicates were removed and of the 916 texts remaining, 770 were excluded by title and abstract screening. A further 13 texts were identified from hand

searching in the reference lists of included sources and 7 from the grey literature search. 146 full texts were reviewed and cross-checked. 51 of these met the criteria for inclusion.  Reasons for full text exclusion are also reported in Figure 3.1.

**Figure 3.1:** Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Diagram (Page *et al.*, 2021)



## Characteristics of Sources Included in the Scoping Review

Fifty-one sources were included in the review, of which *n* = 42 (82%) used qualitative, *n* = 4 (8%) quantitative and *n* = 5 (10%) a combination of both methods. European countries were most represented (*n* = 31), however there was wide global representation: USA (*n* = 9), Australia and New Zealand (*n* = 8), South America (*n* = 2), Canada (*n* = 3), Asia (*n* = 2) and South Africa (*n* = 1). Included sources were published between 1990 and 2023. An increase in interest on this topic was observed over time with *n* = 16 (31%) of all included sources published between 2021 and 2023 (Figure 3.2).

1694 healthcare professionals were represented from fifteen different professional backgrounds (Figure 3.3). Medical *n* = 558 (33%) and nursing *n* = 537 (32%) professionals were more highly represented than allied health or social care professionals *n* = 310 (18%) combined. Profession or discipline was not reported for *n* = 288 (17%).

Professionals were identified as working in six main healthcare settings. The majority of included sources *n* = 32 (63%) recruited professionals from a single healthcare setting and only *n* =10 (19%) recruited professionals from 3 or more different settings. Hospice and palliative care were most highly represented in *n* = 20 sources, followed by community/primary care (*n* = 18), hospital (*n* = 17) and specialist MDT clinics (*n* = 15). Voluntary organisations (*n* = 4) and residential care facilities (*n* = 2) were least commonly represented (Figure 3.4). See all characteristics of included sources in Appendix D.

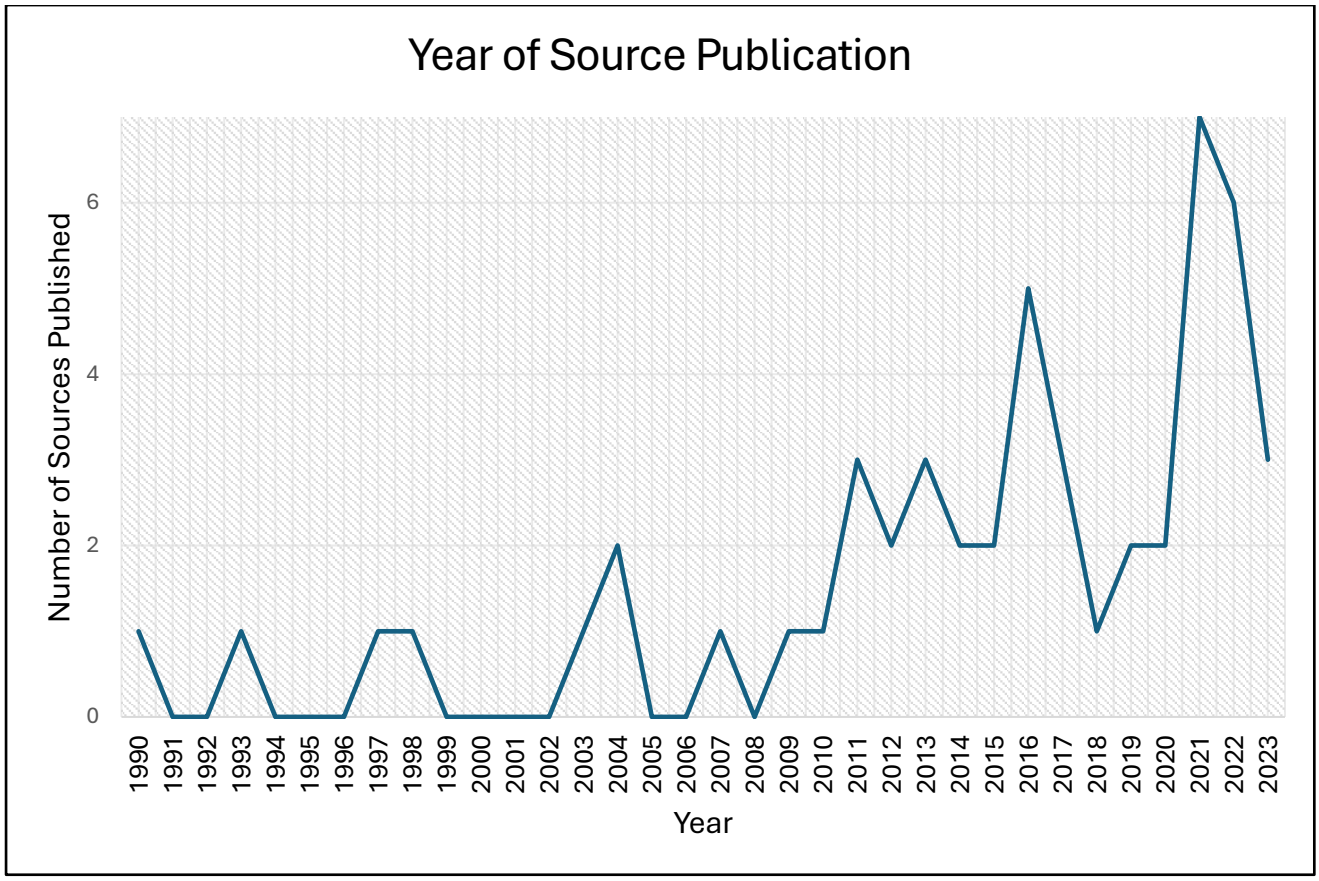



**Figure 3.2:** Line Graph Representing Publication Dates of Sources Included in the Scoping Review

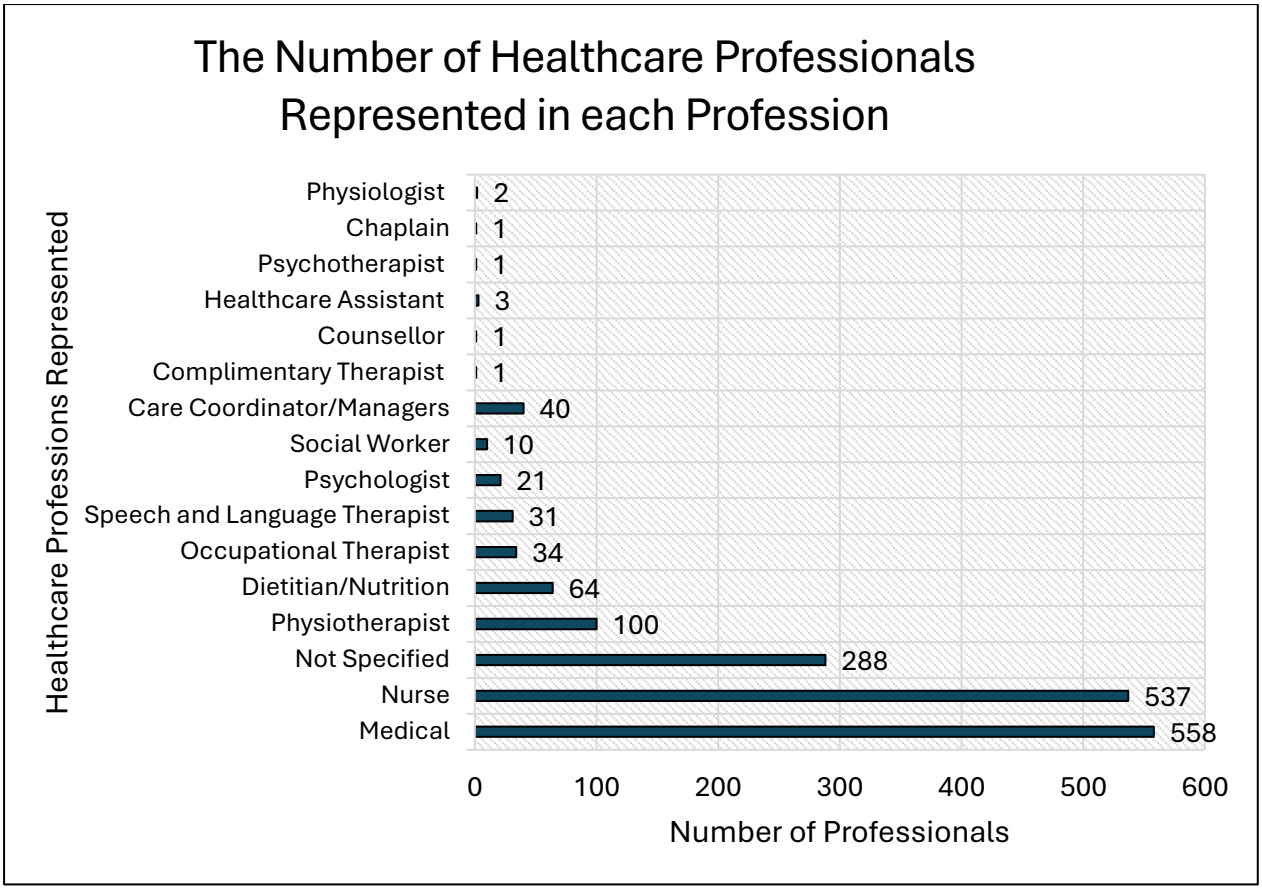



**Figure 3.3:** Bar Chart Outlining the Number of Healthcare Professionals Within Each of the Represented Professions in the Scoping Review

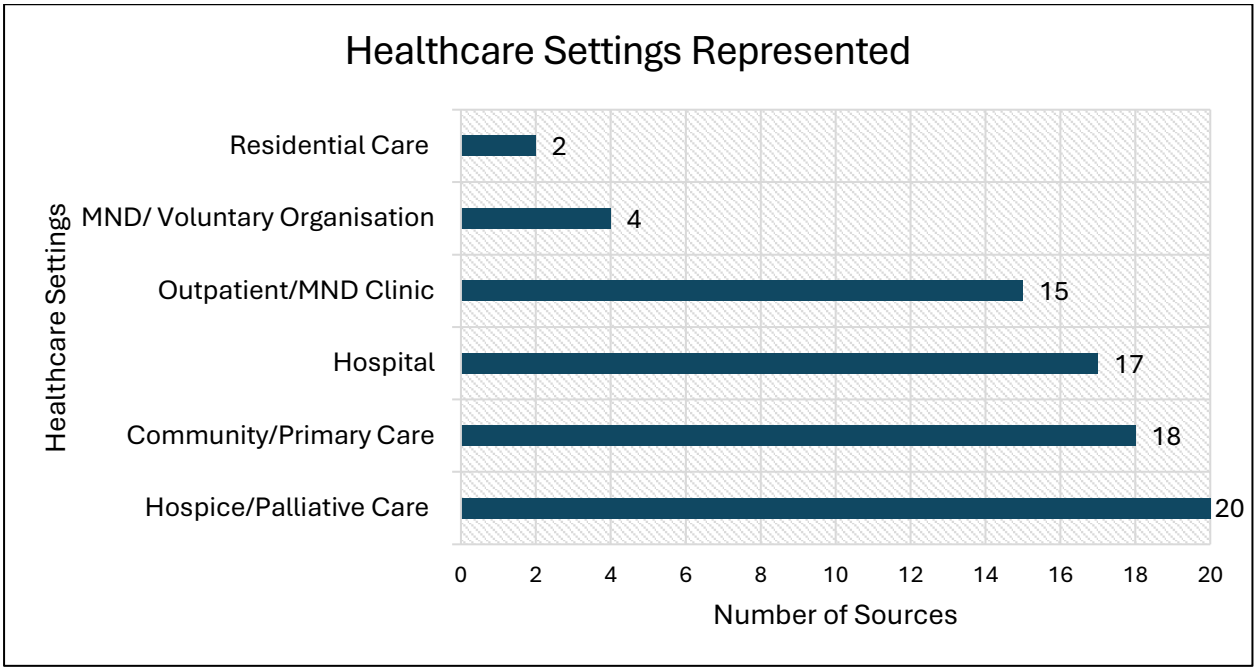



**Figure 3.4:** Bar Chart Representing the Frequency of Key Service Representation in The Sources Included in the Scoping Review

### 3.3.2 Results of the Qualitative Synthesis

Three main categories were generated from the material reviewed: (1) The demands of providing motor neurone disease care (2) factors influencing professionals' ability to provide desired levels of care (Figure 3.5) (3) The emotional impact of working with MND(Table 3.2). Sub-categories are depicted within each of these.

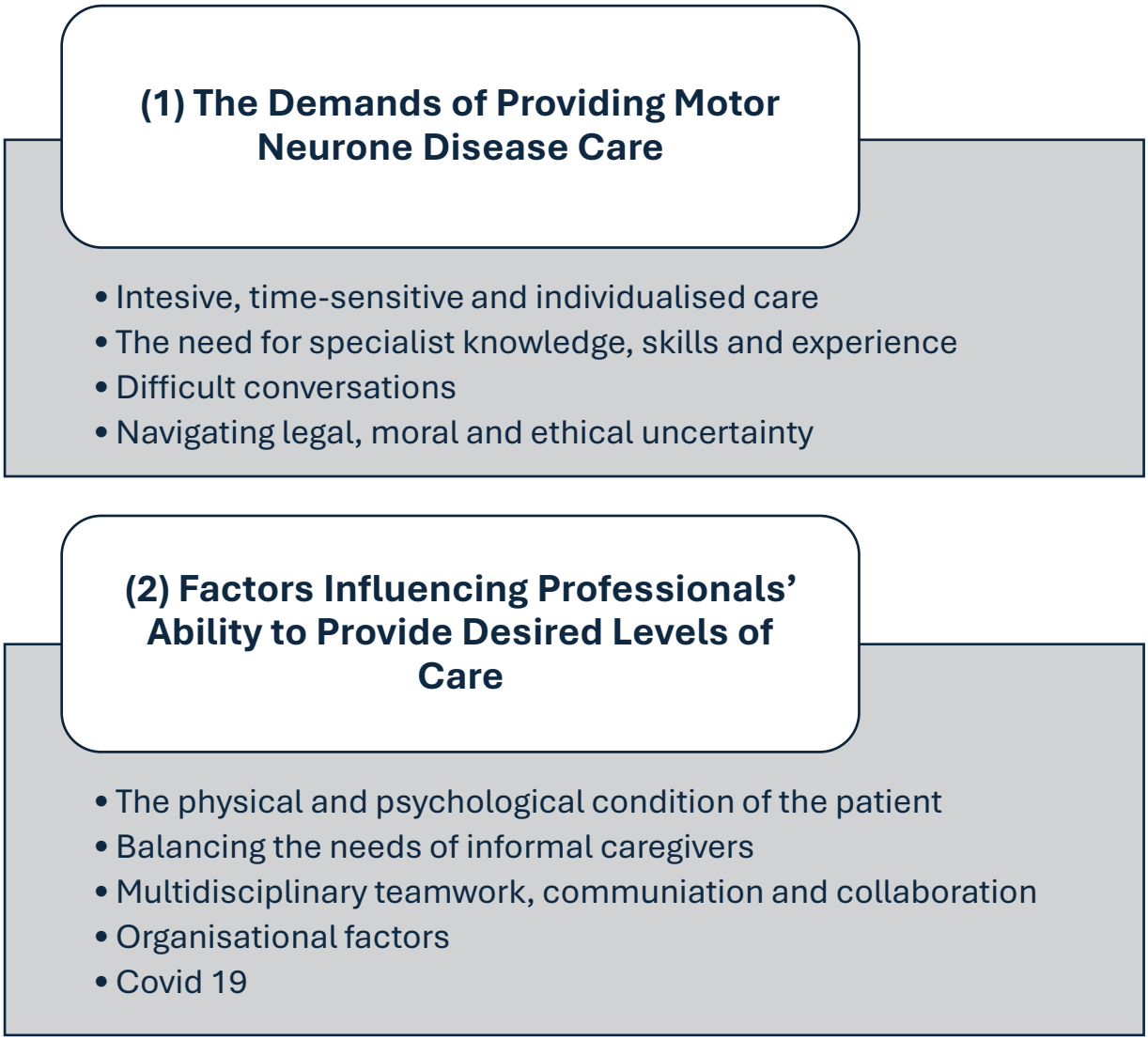



**Figure 3.5**: Overview of Categories One and Two and The Sub-Categories Within Each Main Category

### 3.3.2.1 Category 1: The Demands of Providing Motor Neurone Disease Care

#### Intensive, time-sensitive and individualised care

Providing care for plwMND and their families required exceptional multidisciplinary team effort (Cutler, 2009; LeBon and Fisher, 2011; Lerum, Solbraekke and Frich, 2017; O'Brien and O'Brien, 2022). Professionals described going above their '*usual practice'* or '*typical role'* to meet the complexity and extent of patient care needs (Carroll-Thomas, 1993; Brown, 2003; Hughes *et al.*, 2005 ; Cutler, 2009; Faull, Regen and Phelps, 2016; Phelps *et al.*, 2017, 2022). Their care was described as distinctive and often prioritised over patients with other conditions (Hughes *et al.*, 2005 ; McConigley *et al.*, 2014; Lerum, Solbraekke and Frich, 2017; Daneau *et al.*, 2023). Some professionals were described as committed and passionate (Hennessey, 2016; Coates *et al.*, 2021; Ushikubo *et al.*, 2021), while others avoided working with this population due to the perceived complexity (Lerum, Solbraekke and Frich, 2017). Nurses particularly described the intensity of care as physically and mentally exhausting and the associated workload as limiting their capacity to care for other patients (Erlen, Burger and Tesone, 1990; Ushikubo *et al.*, 2021; Beyermann *et al.*, 2023). In one source the unequal time nurses had to give to those with MND, over others in their care, caused them '*ethical discomfort'* and they felt that reduced patient-to-nurse ratios were required to provide safe and quality care for these patients (Beyermann *et al.*, 2023).

The continuous, heterogeneous, unpredictable, and often rapid nature of disease progression is a unique feature of MND, that contributed to professionals feeling under *'time pressure'* and '*working within windows of opportunity*' (Brown, 2003; Hughes *et al.*, 2005; Hogden *et al.*, 2012; Ushikubo and Okamoto, 2012; Baxter *et al.*, 2013; McConigley *et al.*, 2014; Bakker *et al.*, 2015; Brewah, 2019; Zarotti *et al.*, 2019; Chapman, Bayes and Sim, 2021; Coates *et al.*, 2021; Olesen *et al.*, 2022; Daneau *et al.*, 2023). Professionals in many sources reported having inadequate time to address all the clinical needs MND patients presented with (Erlen, Burger and Tesone, 1990; Brown, 2003; Bromberg, Schenkenberg and Brownell, 2011; LeBon and Fisher, 2011;

Faull, Haynes and Oliver, 2013; Siewers, Holmoy and Frich, 2013; McConigley *et al.*, 2014; Martin *et al.*, 2016; Crockford, Stockton and Abrahams, 2017; Phelps *et al.*, 2017; S. Aoun *et al.*, 2018; Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021; Coates *et al.*, 2021; Ushikubo *et al.*, 2021; Phelps *et al.*, 2022; Olesen *et al.*, 2022; Daneau *et al.*, 2023). Professionals could feel overwhelmed by the multitude of clinical problems (Erlen, Burger and Tesone, 1990; Gamskjaer, Werlauff and Handberg, 2022) and perceived the duration of standard appointments as insufficient to adequately address all identified issues (Crockford, Stockton and Abrahams, 2017; Coates *et al.*, 2021). Homecare nurses in one source felt able to provide adequate person-centred care, because of additional time available to them (Bakker *et al.*, 2015).

Interventions and care needed to be individualised for each patient and family (Brown, 2003; McConigley *et al.*, 2014; Hennessey, 2016; Martin *et al.*, 2016; James *et al.*, 2018; Chapman, Bayes and Sim, 2021; Alquati *et al.*, 2022; Phelps *et al.*, 2022). Developing relationships with patients and families was important to understand their needs and priorities and facilitate an individualised approach to their care (Brown, 2003; Cutler, 2009; Lerum, Solbraekke and Frich, 2017; Coates *et al.*, 2021; Beyermann *et al.*, 2023). Professionals expressed concerns about quality of care in the absence of a patient-provider relationship (Lerum, Solbraekke and Frich, 2017). However, they acknowledged that developing and sustaining relationships with these patients and families required emotional effort and adjusting their demeanour and approach for each individual situation was challenging (Brown, 2003).

### The need for specialist knowledge, skills, and experience

Having up to date knowledge about the condition and available treatments was essential (Carter *et al.*, 1998; Brown, 2003; McConigley *et al.*, 2014; Zarotti *et al.*, 2019; Olesen *et al.*, 2022) as patients hope for a cure, meant they often sought information from multiple sources (Hogden *et al.*, 2012) and were interested in ongoing research (Dengler and Troger, 1997). Keeping up to date with evidence and the availability of services was difficult for professionals who provided this care

infrequently (Brown, 2003; McConigley *et al.*, 2014; Zarotti *et al.*, 2019). One General Practitioner stated:

'*the clients with MND usually know about them [treatments] before us… you know they're on the internet'*(McConigley *et al.*, 2014).

Professionals who specialised in MND care valued having specific and profound knowledge (Gamskjaer, Werlauff and Handberg, 2022), while access to expert knowledge was important to those who encountered the condition less frequently (Olesen *et al.*, 2022; Daneau *et al.*, 2023).

In many sources, professionals acknowledged their limitations in having the required skills and experience to confidently provide MND care (Brown, 2003; McConigley *et al.*, 2014; Crockford, Stockton and Abrahams, 2017; Zarotti *et al.*, 2019; de Carvalho Costa *et al.*, 2020; Olesen *et al.*, 2022; Phelps *et al.*, 2022). Nurses reported needing to draw on all their nursing skills to meet the associated challenges (Cutler, 2009; Daneau *et al.*, 2023). In one source, professionals felt significantly less confident managing patients with MND than those with a less progressive neurological conditions (Carter *et al.*, 1998). Lack of confidence with the use of medical equipment, assistive devices and technology commonly used by these patients was also discussed (Siewers, Holmoy and Frich, 2013; Lerum, Solbraekke and Frich, 2017; Olesen *et al.*, 2022).

Some felt that previous experience allowed them to provide greater hope and optimism for MND patients and their families. They felt able to talk about what could be done to manage symptoms and offer solutions rather than just seeing barriers (Carter *et al.*, 1998; Olesen *et al.*, 2022). More years of experience was related to lower levels of stress for doctors and clinic managers in one source (Bromberg, Schenkenberg and Brownell, 2011), while neurologists who were not experiencing burnout were working with MND for longer than those experiencing burnout in another (Hennessey, 2016). Many professionals felt that most of what they learned about providing MND care was through their prior clinical experiences (Brown, 2003; Hennessey, 2016; Coates *et al.*, 2021; Phelps *et al.*, 2022); others felt that previous

experience did not necessarily help with the most challenging aspects, such as end-of-life care conversations (Chapman, Bayes and Sim, 2021).

## Difficult conversations

In one source 65% of neurologists reported '*moderate-high'* levels of stress and anxiety on delivering the diagnosis and 43% reported finding it '*very – somewhat'* difficult responding to patients' emotional reaction to the diagnosis (Aoun *et al.*, 2016). Neurologists in another source reported this to be the most emotionally challenging aspect of their job and that delivering more than three diagnoses in a day, could leave them emotionally and physically exhausted (Hennessey, 2016). 73% struggled to reveal the diagnosis to a patient they personally identified with because of a demographic similarity such as age, gender, family composition or career; one neurologist reported '*having a migraine after each MND clinic and feeling stressed and anxious about having so little to offe*r' (Aoun *et al.*, 2016). In multiple sources, professionals struggled because of the lack of a cure for this disease (Dengler and Troger, 1997; Carter *et al.*, 1998; Aoun *et al.*, 2016; Hennessey, 2016; Olesen *et al.*, 2022).

Eight sources discussed the dilemma professionals faced when determining the appropriate time to introduce conversations about advanced care planning, palliative or end-of-life care (Carroll-Thomas, 1993; Hogden *et al.*, 2012; Baxter *et al.*, 2013; Faull, Haynes and Oliver, 2013; Ruffell *et al.*, 2013; Martin *et al.*, 2016; Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021). Professionals aimed to start these conversations early, recognising that skilled communication and good clinical judgement was required to determine the appropriate time for each individual (Carroll-Thomas, 1993; Hogden *et al.*, 2012; Ruffell *et al.*, 2012; Baxter *et al.*, 2013; Faull, Regen and Phelps, 2016; Martin *et al.*, 2016; Cipolletta and Reggiani, 2021). This involved considering factors such as the rate of disease progression, social factors, coping and acceptance, and challenged even those experienced in delivering MND care (Martin *et al.*, 2016). Professionals found it difficult to provide honest

information without taking away the person's sense of hope or optimism (Carter *et al.*, 1998; Hogden *et al.*, 2012; Hennessey, 2016; Aoun *et al.*, 2018). They feared causing additional distress and wanted to avoid '*piling on the bad news'* (Gray and Abrahams, 2022; Daneau *et al.*, 2023).

Conversations about end-of-life could be uncomfortable, overwhelming, and, sometimes avoided by professionals (Oliver and Turner, 2010; Faull, Haynes and Oliver, 2013; Daneau *et al.*, 2023), with some families wanting to discuss issues such as euthanasia and physician assisted suicide (Phelps *et al.*, 2017). Professionals experienced anxiety about engaging patients in conversations about advance care planning when they were still relatively well (Gale, 2015). Being comfortable talking about end-of-life (McConigley *et al.*, 2014) and having a positive perspective on working with death was considered helpful, but difficult, for some (Gamskjaer, Werlauff and Handberg, 2022). Professionals perceived that a big part of their job was often '*to be present without intervening*'(Gamskjaer, Werlauff and Handberg, 2022), '*to be a listener'* (Brown, 2003) , '*simply allowing them to be sad*' (Gamskjaer, Werlauff and Handberg, 2022) or '*taking on the burden of grief*'(Brown, 2003; Hennessey, 2016; Daneau *et al.*, 2023). Those working in specific palliative care positions were more comfortable with difficult conversations about signs of deteriorating health, than those without palliative care experience (Carter *et al.*, 1998; LeBon and Fisher, 2011; Daneau *et al.*, 2023).

## Navigating legal, moral and ethical uncertainty

Legal, moral and ethical dilemmas were frequently described in relation to decision making, planning, communicating and managing end-of-life care (LeBon and Fisher, 2011; Ushikubo and Okamoto, 2012; Faull, Haynes and Oliver, 2013; Gale, 2015; Phelps *et al.*, 2017; Cipolletta and Reggiani, 2021; Phelps *et al.*, 2022; O'Brien and O'Brien, 2022; Daneau *et al.*, 2023). The withdrawal of non-invasive ventilation raised significant legal, moral and ethical concerns for professionals involved in this process (LeBon and Fisher, 2011; Faull, Haynes and Oliver, 2013; Phelps *et al.*, 2017, 2022). The legal and ethical complexity was compounded when the underlying

reason for the patient requesting ventilation withdrawal was their wish to die, rather than the removal of burdensome treatment (Phelps *et al.*, 2017, 2022). Several sources also discussed the ethical dilemma professionals faced between respecting patient autonomy and beneficence (Erlen, Burger and Tesone, 1990; Carroll-Thomas, 1993; Oliver, 2004; Ushikubo and Okamoto, 2012; Olesen *et al.*, 2022; O'Brien and O'Brien, 2022). Circumstances were described when professionals were faced with complex ethical dilemmas between supporting patient wishes and ensuring their own, the patients or informal caregivers' safety or welfare (Erlen, Burger and Tesone, 1990; Ushikubo and Okamoto, 2012; Olesen *et al.*, 2022).

#### 3.3.2.2 Category 2: Factors Influencing Professionals' Ability to Provide Desired Levels of Care

##### The physical and psychological condition of the patient

The rate of disease progression could impact the quality of care provided (Ushikubo and Okamoto, 2012; Baxter *et al.*, 2013; Faull, Haynes and Oliver, 2013; Bakker *et al.*, 2015; Coates *et al.*, 2021). Professionals described situations when the patient's condition changed more rapidly or abruptly than expected, rendering current supportive measures immediately ineffective (Baxter *et al.*, 2013; Zarotti *et al.*, 2019). Professionals were required to respond rapidly to what were described as '*crisis*' situations (Hogden *et al.*, 2012; McConigley *et al.*, 2014). With a slower rate of progression, the need for assistive devices, home care services and other supports were less acute, and professionals had time to effectively plan and support their implementation (Bakker *et al.*, 2015). Professionals highlighted the need to take a proactive or anticipatory approach to deliver good care for these patients (Carroll-Thomas, 1993; Hogden *et al.*, 2012; Ruffell *et al.*, 2013; McConigley *et al.*, 2014; Martin *et al.*, 2016; Coates *et al.*, 2021; Rolland, Myrberget and Meisingset, 2021; Alquati *et al.*, 2022). They aimed to stay *'one step ahead'* by anticipating, planning, and preparing for interventions before they were required (Carroll-Thomas, 1993; Hogden *et al.*, 2012; McConigley *et al.*, 2014; Martin *et al.*, 2016) and described how situations could spiral into *'chaos'* when professionals were unprepared or uncertain

about the trajectory of deterioration (McConigley *et al.*, 2014; Lerum, Solbraekke and Frich, 2017; Chapman, Bayes and Sim, 2021).

Patient psychological adjustment and coping was discussed in thirteen sources (Carter *et al.*, 1998; Hughes *et al.*,2005 ; Hogden *et al.*, 2012; Bakker *et al.*, 2015; Gale, 2015; Martin *et al.*, 2016; Lerum, Solbraekke and Frich, 2017; Zarotti *et al.*, 2019; Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021; Coates *et al.*, 2021; Hetzler, 2021; Daneau *et al.*, 2023). Acceptance (Hughes *et al.*,2005; Hogden *et al.*, 2012; Martin *et al.*, 2016; Coates *et al.*, 2021; Alquati *et al.*, 2022) and denial (Hogden *et al.*, 2012; Martin *et al.*, 2016; Lerum, Solbraekke and Frich, 2017; Zarotti *et al.*, 2019; Chapman, Bayes and Sim, 2021; Daneau *et al.*, 2023) were raised as enablers and barriers to the level of care that could be provided. How patients adjusted to the diagnosis or deterioration in their condition influenced when interventions were provided. Patient and family acceptance of the diagnosis could influence clinician's stress levels. Patients with some degree of acceptance of their condition, were perceived as more open to discussions, engaged in decision making and pro-active in managing their symptoms (Martin *et al.*, 2016; Zarotti *et al.*, 2019).

The '*need for control*' could vary between patients, for some it manifested as taking control of managing their condition while for others it was exerted as avoidance or disengagement (Zarotti *et al.*, 2019). Professionals encountered patients who were in denial or shock at the terminal nature of the diagnosis and avoided engaging with services. This was frustrating, as it significantly limited their ability to deliver what was perceived as good anticipatory care (Hogden *et al.*, 2012; Crockford, Stockton and Abrahams, 2017; Cipolletta and Reggiani, 2021).

Professionals found it challenging to manage cognitive and behavioural symptoms MND patients presented with (Hennessey, 2016; Crockford, Stockton and Abrahams, 2017). Cognitive and behavioural changes impacted patients' understanding of information and the quality and timing of their healthcare decision making (Hogden *et al.*, 2012; Hennessey, 2016; Chapman, Bayes and Sim, 2021; Coates *et al.*, 2021; Ushikubo *et al.*, 2021; Gray and Abrahams, 2022). It also impacted their ability to use aids and devices such as high-tech communication aids and powered wheelchairs (Ushikubo *et al.*, 2021; Gray and Abrahams, 2022). Professionals felt that patients

who received cognitive and behavioural screening, received better clinical care, as their difficulties were identified and validated (Hogden *et al.*, 2012; Gray and Abrahams, 2022); without routine cognitive screening, mild cognitive changes were not always identified (Hogden *et al.*, 2012). Professionals felt that more specific and detailed knowledge of these symptoms could improve their approach with these patients (Hogden *et al.*, 2012).

The presence of communication impairments presented particular challenges (Carter *et al.*, 1998; Cutler, 2009; McConigley *et al.*, 2014; Brewah, 2019; Daneau *et al.*, 2023). Professionals highlighted that having knowledge of communication devices and how to effectively use them was essential to provide good care (McConigley *et al.*, 2014; Brewah, 2019) and that training for professionals on how to use these devices should be addressed (Brewah, 2019). Understanding patient's wishes, ensuring they were appropriately included in discussions and respecting their autonomy was challenging when communication was a problem (Ushikubo and Okamoto, 2012; Faull, Haynes and Oliver, 2013; Phelps *et al.*, 2017; Brewah, 2019; Daneau *et al.*, 2023).

## Balancing the needs of informal caregivers

Professionals recognised the important role of informal carers and the exhausting level of care they often provided (Brown, 2003; Ushikubo and Okamoto, 2012; McConigley *et al.*, 2014; Beyermann *et al.*, 2023); '*The heavy care burden brought the family to the verge of ruin'* (Ushikubo and Okamoto, 2012). Professionals reported difficulty assessing how much strain the family could manage (Lerum, Solbraekke and Frich, 2017) and providing emotional support and hope, in the face of deteriorating illness (Olesen *et al.*, 2022; Beyermann *et al.*, 2023). They were exposed to '*a lot of tears, frustrations and helplessness'* (Olesen *et al.*, 2022) and found it *'awful to look at'* (Lerum, Solbraekke and Frich, 2017) the emotional distress and burden family members experienced (Beyermann *et al.*, 2023). Some felt pressured for time or lacked knowledge about how best to support families (Olesen *et al.*, 2022; Beyermann *et al.*, 2023).

It was important for professionals to develop good relationships with family caregivers as in many cases they were the conduit between the patient and the care team (McConigley *et al.*, 2014; Beyermann *et al.*, 2023; Daneau *et al.*, 2023). Professionals described collaboration with families as a balancing act and often encountered dilemmas and family dynamics (Oliver and Turner, 2010; Hogden *et al.*, 2012; Ushikubo and Okamoto, 2012; Hennessey, 2016; Martin *et al.*, 2016; Olesen *et al.*, 2022; Beyermann *et al.*, 2023; Daneau *et al.*, 2023). Lack of concordance between the wishes of the patient and their family made things more difficult for the team supporting them (Martin *et al.*, 2016). Decision making was challenging when the patient and their family could not reach agreement, patient's decision-making placed family members at risk,(Hogden *et al.*, 2012; Beyermann *et al.*, 2023) or family members engaged in activities that were deemed unsafe for the patient. Professionals were required to take both sides into account:

''*I don't think you can only talk to the person with ALS and find out just what they want, because what their carer wants might be totally different… The client might say I want to stay at home, it's the only thing I want to do', and the partner might be going 'there is no way I can handle physically their behaviours'. So, you've got to take both into consideration'* (Hogden *et al.*, 2012).

## Multidisciplinary teamwork, communication and collaboration

Managing the complex needs of MND patients and their families, required a large team and a union of authorities, teams and professionals (McConigley *et al.*, 2014; Olesen *et al.*, 2022). Co-ordinating the number of people involved was a frequently cited challenge (Hogden *et al.*, 2012; Ushikubo and Okamoto, 2012; McConigley *et al.*, 2014; Cipolletta and Reggiani, 2021; Olesen *et al.*, 2022). There could be uncertainty about who's role it was to co-ordinate patient care or the clinician responsible for initiating certain discussions or interventions (Faull, Haynes and Oliver, 2013; Crockford, Stockton and Abrahams, 2017; Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021). Professionals counteracting or duplicating each other's work was experienced when '*one side doesn't know what the other is*

*doing'* (McConigley *et al.*, 2014). Feelings of frustration and powerlessness were experienced by professionals working with external teams who did not assign the same level of priority to MND patient care (Gamskjaer, Werlauff and Handberg, 2022) or refused to provide a service, due to the perceived level of complexity (Lerum, Solbraekke and Frich, 2017; Gamskjaer, Werlauff and Handberg, 2022; Olesen *et al.*, 2022). The need for better communication and transfer of information between the teams and services involved was identified (Hughes *et al.*,2005; McConigley *et al.*, 2014; Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021).

The value of multidisciplinary team working, and strong professional relationships was discussed in twenty-one sources (Carter *et al.*, 1998; Brown, 2003; Oliver, 2004; Mitsumoto and Rabkin, 2007; Cutler, 2009; Oliver and Turner, 2010; LeBon and Fisher, 2011; Hogden *et al.*, 2012; Faull, Haynes and Oliver, 2013; Bakker *et al.*, 2015; Hennessey, 2016; Phelps *et al.*, 2017, 2022; Brewah, 2019; Cipolletta and Reggiani, 2021; Gamskjaer, Werlauff and Handberg, 2022; Musson *et al.*, 2022; Olesen *et al.*, 2022; Beyermann *et al.*, 2023; Daneau *et al.*, 2023; Kloos, 2023). Six sources described challenges when there were differences of opinion about how care be provided within the healthcare team (Oliver and Turner, 2010; Ushikubo and Okamoto, 2012; Faull, Haynes and Oliver, 2013; Crockford, Stockton and Abrahams, 2017; Phelps *et al.*, 2017, 2022). Effective teamworking was important for professionals and contributed to their job satisfaction (Gamskjaer, Werlauff and Handberg, 2022; Kloos, 2023). When professionals worked in what they perceived as a well-functioning multidisciplinary team, they felt enabled to deliver effective support and care for patients and their families (Oliver and Turner, 2010; Musson *et al.*, 2022; Olesen *et al.*, 2022). Professionals also recognised the emotional support they received from working within a strong multidisciplinary model of care (Oliver, 2004; Mitsumoto and Rabkin, 2007; Cutler, 2009; Oliver and Turner, 2010; Hennessey, 2016; Phelps *et al.*, 2017; Gamskjaer, Werlauff and Handberg, 2022; Beyermann *et al.*, 2023). Professionals reported that collegial support was invaluable in helping them to process *'heavy'* thoughts and emotions that arose from the difficult situations they were faced with when working with these patients (Gamskjaer, Werlauff and Handberg, 2022). In the absence of team support professionals

reported feeling overwhelmed (Erlen, Burger and Tesone, 1990) vulnerable (Phelps *et al.*, 2022) and isolated (Lerum, Solbraekke and Frich, 2017) when faced with making decisions or providing care alone. This was particularly relevant for nurses and healthcare assistants providing care in patient's homes (Erlen, Burger and Tesone, 1990; Lerum, Solbraekke and Frich, 2017; Beyermann *et al.*, 2023).

## Organisational factors

Ten sources referenced lack of personnel or high rates of staff turnover as a problem for delivering consistent and high-quality care (Erlen, Burger and Tesone, 1990; Brown, 2003; Bromberg, Schenkenberg and Brownell, 2011; Hennessey, 2016; Crockford, Stockton and Abrahams, 2017; Lerum, Solbraekke and Frich, 2017; James *et al.*, 2018; Coates *et al.*, 2021; Gray and Abrahams, 2022; Daneau *et al.*, 2023). 29% of neurologists and 34% of MND clinic managers in one source considered leaving their position due to stress or financial issues (Bromberg, Schenkenberg and Brownell, 2011). High rates of turnover resulted in inconsistent team composition and prevented important aspects of care from being delivered, (Erlen, Burger and Tesone, 1990; Crockford, Stockton and Abrahams, 2017; Lerum, Solbraekke and Frich, 2017; James *et al.*, 2018; Coates *et al.*, 2021; Gray and Abrahams, 2022) for example, lack of neuropsychologists prevented routine cognitive assessment in multidisciplinary clinics (Gray and Abrahams, 2022).

It could be challenging to recruit professionals to work with MND patients, as '*people avoided'* working with this patient group. High levels of turnover made it challenging to develop professionals' expertise and retain professionals with the required level of competency to meet the demands of MND patient care (Lerum, Solbraekke and Frich, 2017). With low staff turnover, professionals established a connection with their patients that allowed them to gather sensitive and personal information about their care preferences and this was considered essential to providing good person-centred care (Lerum, Solbraekke and Frich, 2017).

Availability of finances, resources, access to services and assistive devices were identified as barriers by professionals in fourteen sources (Erlen, Burger and Tesone,

1990; Dengler and Troger, 1997; Carter *et al.*, 1998; Brown, 2003; Bromberg, Schenkenberg and Brownell, 2011; Casey, 2011; LeBon and Fisher, 2011; Hennessey, 2016; Crockford, Stockton and Abrahams, 2017; Lerum, Solbraekke and Frich, 2017; James *et al.*, 2018; Coates *et al.*, 2021; Hetzler, 2021; Rolland, Myrberget and Meisingset, 2021). Geographical variation in funding and services available impacted equitable service delivery (Crockford, Stockton and Abrahams, 2017; Coates *et al.*, 2021; Rolland, Myrberget and Meisingset, 2021). Professionals identified that standard pathways for accessing services and medical devices were inappropriate for these patients (Dengler and Troger, 1997; Hogden *et al.*, 2012). Long delays with administration and obtaining financial approval was more problematic for this population than other less quickly progressing diseases (Dengler and Troger, 1997). A number of sources discussed how bureaucratic processes resulted in patients receiving necessary medical aids or devices after the disease had further progressed and the device was no longer suitable (Dengler and Troger, 1997; Brown, 2003; Casey, 2011; Hogden *et al.*, 2012; Lerum, Solbraekke and Frich, 2017; Hetzler, 2021; Rolland, Myrberget and Meisingset, 2021). Professionals found this stressful, (Hogden *et al.*, 2012) while organisational factors such as being understaffed and institutional demands contributed to others experiencing burnout (Hennessey, 2016).

### Covid 19

HCPs' experiences of delivering MND care for patients during the COVID-19 pandemic was discussed in three sources from 2020 – 2022 (Andrews *et al.*, 2020; Musson *et al.*, 2022; O'Brien and O'Brien, 2022). Enforcing visiting restrictions was described as causing '*palpable distress*' and '*emotional devastation'* for members of a palliative care team involved in the care of a young lady with MND. This case was identified as an '*exceptional case*' and '*ethically challenging'* for the staff involved, due to the patient's MND associated communication impairment. She could not use technology to engage with her family, as others could, and staff viewed the restrictions imposed as '*wrong on so many levels*' (O'Brien and O'Brien, 2022).

Specialists' ability to carry out important assessments, such as the physical examination required to confirm the diagnosis and spirometry testing, one of the key

assessments for monitoring disease progression could not be completed virtually (Andrews *et al.*, 2020). Professionals reported feeling concerned about missing important clinical details and the impact of this on the patient's quality-of-life and survival (Musson *et al.*, 2022). Professionals also experienced delayed access to key services including gastrostomy insertion, provision of wheelchairs and home help and hospice services being unavailable at certain times (Andrews *et al.*, 2020). Professionals described how they developed new models of service delivery to overcome many of these challenges, but some expressed reduced confidence in their ability to deliver optimal care during this time (Musson *et al.*, 2022).

#### 3.3.2.3 Category 3: The Emotional Impact of Working with Motor Neurone Disease

Many sources referenced the emotional involvement for professionals working with MND (Carter *et al.*, 1998; Brown, 2003; Mitsumoto and Rabkin, 2007; Oliver and Turner, 2010; Bromberg, Schenkenberg and Brownell, 2011; LeBon and Fisher, 2011; Faull, Haynes and Oliver, 2013; Faull, Regen and Phelps, 2016; Hennessey, 2016; Phelps *et al.*, 2017; Brewah, 2019; Andrews *et al.*, 2020; de Carvalho Costa *et al.*, 2020; Cipolletta and Reggiani, 2021; Hetzler, 2021; Phelps *et al.*, 2022; Gamskjaer, Werlauff and Handberg, 2022; O'Brien and O'Brien, 2022; Beyermann *et al.*, 2023; Daneau *et al.*, 2023). A full overview of the emotional and psychological responses described are provided in Table 3.2. Professionals reported needing to disengage their personal feelings (Faull, Regen and Phelps, 2016; O'Brien and O'Brien, 2022) and using compartmentalisation as a coping mechanism, whereby they avoided thinking about work situations outside of work, many felt they would not be able to continue in their role otherwise (Hennessey, 2016):

'*I kind of have to separate a bit emotionally because obviously I wouldn't be able to survive'* (Hennessey, 2016)

Other professionals, particularly those who spent a lot of time with patients such as clinical specialists, homecare nurses and primary care teams reported developing close relationships and for some an emotional connection or bond (Brown, 2003;

Mitsumoto and Rabkin, 2007; LeBon and Fisher, 2011). These professionals could feel profound loss on the patient's death (Mitsumoto and Rabkin, 2007; LeBon and Fisher, 2011). In one source, 66% of neurologists and 94% of clinic managers contacted a patient's family after their death and 25% of neurologists and 55% of clinic managers attended patient funerals (Bromberg, Schenkenberg and Brownell, 2011), another neurologist reported:

*'I don't go to funerals; it's kind of like my line. I can be sad with the patient and the family all the way to their death, but I just can't go to a funeral a week… it's just too much for me'* (Hennessey, 2016).

Professionals discussed how some cases affected them more than others, such as when the disease progressed quickly, or patients were younger (Gamskjaer, Werlauff and Handberg, 2022). Others found it emotionally challenging to witness patient and family suffering (Lerum, Solbraekke and Frich, 2017; de Carvalho Costa *et al.*, 2020). Professionals described how it could be hard to leave their jobs behind when they were not working (Olesen *et al.*, 2022) and that episodes from work could occupy their minds in their private lives (Gamskjaer, Werlauff and Handberg, 2022). In two sources professionals reported lack of preparation and education about how to manage the emotional and moral suffering they experienced from working with these patients (Oliver and Turner, 2010; Hogden *et al.*, 2012).

Five sources discussed the profound emotional intensity for professionals involved in withdrawing non-invasive ventilation (LeBon and Fisher, 2011; Faull, Haynes and Oliver, 2013; Faull, Regen and Phelps, 2016; Phelps *et al.*, 2017, 2022). Professionals reported a huge emotional strain planning for the withdrawal, '*it felt like setting a date for someone to die'* (Phelps *et al.*, 2022) and '*a personal sadness'* after the withdrawal had taken place (Faull, Regen and Phelps, 2016). In a study of UK doctors over half of the respondents rated the emotional challenge of withdrawing ventilation as 7/10 with over 20% rating this as 9/10 on the scale (Phelps *et al.*, 2017). Three studies reported the lasting effects on professionals involved in this process with some reporting vivid memories that stayed with them for years after the event (Faull, Regen and Phelps, 2016; Phelps *et al.*, 2017, 2022).

Nine sources discussed a sense of job satisfaction and reward that professionals experienced from working with MND patients (Cutler, 2009; Bromberg, Schenkenberg and Brownell, 2011; Hennessey, 2016; de Carvalho Costa *et al.*, 2020; Hetzler, 2021; Gamskjaer, Werlauff and Handberg, 2022; Phelps *et al.*, 2022; Daneau *et al.*, 2023; Kloos, 2023). Professionals described how they felt privileged to be in the position to support patients and families through a difficult time, help them when they '*needed it most'* (Cornwell, 2016; Hennessey, 2016; Hetzler, 2021; Gamskjaer, Werlauff and Handberg, 2022; Phelps *et al.*, 2022) and felt appreciated by the level of gratitude they received (Hennessey, 2016; Hetzler, 2021; Gamskjaer, Werlauff and Handberg, 2022; Beyermann *et al.*, 2023).

'*you really get so much in return, you know, when you are in the midst of all the hopelessness – you actually feel the appreciation or gratitude coming from the patient or the relative*'(Gamskjaer, Werlauff and Handberg, 2022)

In two sources professionals reported that a benefit of their work was the life and death scenarios they encountered, gave them greater perspective and appreciation for their own personal lives (Hennessey, 2016; Gamskjaer, Werlauff and Handberg, 2022).

**Table: 3.2:** Emotional and Psychological Responses Described by Healthcare Professionals in Included Sources

| Emotional or Psychological Response | Examples of Quotations | Additional Sources of Reference: |
|---|---|---|
| **Stress** | *"I do find the rapid transition from living to dying aided by the removal of a life sustaining treatment and supported by respiratory and conscious level depressant drugs to be more stressful than most other areas of practice"* (Faull, Haynes and Oliver, 2013)<br><br>*"It adds real stress when people are clearly progressing, but then you're waiting for something to happen. And in the meantime, they're struggling until that happens. And by the time that thing happens, the thing you've requested is out of date. So, then you're asking for something else"* (Hogden *et al.*, 2012) | (Mitsumoto and Rabkin, 2007; Aoun *et al.*, 2016, 2016b; Phelps *et al.*, 2017, 2022; Cipolletta and Reggiani, 2021; Ushikubo *et al.*, 2021; O'Brien and O'Brien, 2022) |
| **Anxiety** | *"I often perceive a sort of anxiety in wanting the advance treatment directives, especially some colleagues directly involved in some procedures. Something that aims more to compensate for the anxiety of being in an urgent clinical condition and not knowing what to do"* (Alquati *et al.*, 2022)<br><br>*'One neurologist expressed "Having had a migraine after each MND clinic, feeling stressed and anxious about having so little to offer, I have gradually accepted the limitations of my skills and some confidence that assisting the patients honestly and empathetically, and not 'abandoning' them is of most value to most patients"*( Aoun *et al.*, 2016) | (Faull, Haynes and Oliver, 2013; Gale, 2015; Hennessey, 2016; Phelps *et al.*, 2017, 2022) |
| **Burnout** | *Dr A "The one thing I want to emphasise is that working with these patients has always been hard.. in this line of work where every person with the disease will die eventually.. I feel like I'm here for the long haul and I want to pace myself, and I* | (Hennessey, 2016) |

| | | |
|---|---|---|
| | *want to pace our team. It's important to recognise one's own vulnerability to burnout and to recognise signs of stress"* (Mitsumoto and Rabkin, 2007) | |
| **Emotional Exhaustion** | **'***Informants described a feeling of being "filled up" and "being emotionally exhausted" when they arrived home after work & how they needed some quiet time alone'* (Gamskjaer, Werlauff and Handberg, 2022)<br>*"The emotional drain was enormous as we are so unused to having that much control over the timing and place of death"* (Faull, Haynes and Oliver, 2013) | (Erlen, Burger and Tesone, 1990; Oliver and Turner, 2010; Faull, Haynes and Oliver, 2013; Hennessey, 2016; Ushikubo *et al.*, 2021; Daneau *et al.*, 2023) |
| **Burden** | **"***We get so affected by it because it's so hopeless & the hopelessness it's such a heavy burden to carry*"(Olesen *et al.*, 2022)<br><br>"*I guess in a way I'm just trying to take the burden from the patient and the caretaker and putting it on myself. And, um carrying that burden, it's very hard for me"* (Hennessey, 2016) | (Brown, 2003; Mitsumoto and Rabkin, 2007; Faull, Haynes and Oliver, 2013; Faull, Regen and Phelps, 2016; Hennessey, 2016; Phelps *et al.*, 2017; Ushikubo *et al.*, 2021; Olesen *et al.*, 2022; Beyermann *et al.*, 2023) |
| **Frustration** | **'***Limitations inclusive of lack of personnel, time and equipment and the external economics which affected care delivery.. led to frustrations* | (Erlen, Burger and Tesone, 1990; Dengler and Troger, |

| | | |
|---|---|---|
| | *for the care professionals due to a limited ability to achieve their ideals of care'* (Brown, 2003)<br><br>*"It's frustrating in a sense because we don't have a defined – a definitive treatment for them"* (Hennessey, 2016) | 1997; Hogden *et al.*, 2012; Hennessey, 2016; Gamskjaer, Werlauff and Handberg, 2022; Olesen *et al.*, 2022) |
| **Loss** | *'Those who specialise in caring for patients with ALS often know their patients for longer than palliative care specialists. Thus, when a patient with ALS dies, the loss experienced by ALS professionals can be even more profound'* (Mitsumoto and Rabkin, 2007) | |
| **Privilege** | ***"****It is a humbling experience and a privilege to be part of so many courageous people's lives"*(Cornwell, 2016)<br><br>*"While it is not easy, each of these moments define why I consider myself incredibly privileged. I am able to help people when they need it most"*(Hetzler, 2021) | (Hennessey, 2016; Gamskjaer, Werlauff and Handberg, 2022; Beyermann *et al.*, 2023; Kloos, 2023) |

## 3.4 Discussion

### 3.4.1 Main Findings

To the best of our knowledge, this is the first review that has comprehensively identified the available literature representing professionals' experience and the emotional and psychological impact of working with MND. 1,692 professionals are represented, from fifteen disciplines and six key healthcare settings. There are few examples of other conditions requiring intervention from this number of professionals and teams, within a typically short trajectory of illness.

From this review it is evident that working with MND is distinctive and more stressful than other areas of practice. The care provided is intensive, time-sensitive and needs to be individualised for each patient and their informal support network. It is necessary to keep up with emerging knowledge and evidence, specialist skills, technology, and aids to meet the evolving needs and expectations of patients and families. Developing trusting relationships with patients and families was seen as important as professionals frequently engaged in difficult and emotionally charged conversations about deteriorating health and future care planning. Complex decision-making also raised significant legal, moral and ethical uncertainty for many professionals involved.

Factors were identified which could restrict or support professionals to provide what they considered high-quality care. These included the physical and psychological condition of the patient, the needs of their informal caregivers, team and collegial support and a range of organisational factors. Three sources also discussed practical and emotional challenges to providing adequate care for this population during the COVID-19 pandemic. This is widely supported in the literature with many professionals experiencing mental health problems and moral injury because of difficulties delivering optimal care for severely unwell patients during this time (Greenberg *et al.*, 2020). Despite the added impact of COVID-19, the emotional and psychological toll for those working with MND was evident before this period, with both positive and negative implications identified in this review.

### 3.4.2 What this Study Adds, Implications for Practice and Future Research

The findings of this review corroborate research outlining the difficulties experienced by MND patients and informal caregivers in their interactions with the healthcare system. Their experience of services as being fragmented and difficult to access (Aoun *et al.*, 2012; Foley, Timonen and Hardiman, 2014) is echoed by professionals in this review. Professionals identified geographical variation in services and funding available ( Crockford, Stockton and Abrahams, 2017), different team compositions and priorities (Hughes et al., 2005), poor communication between teams and services (McConigley *et al.*, 2014), time pressures and varying degrees of professional confidence and experience (Coates *et al.*, 2021) as limiting their ability to provide adequate levels of care in some circumstances. Feelings of powerlessness and frustration were expressed by professionals in several situations when they felt constrained in their ability to efficiently meet their patient's needs (Brown, 2003; Hogden *et al.*, 2012; Gamskjaer, Werlauff and Handberg, 2022; Olesen *et al.*, 2022). Organisational factors were also attributable to experiences of stress and burnout (Bromberg, Schenkenberg and Brownell, 2011; Hogden *et al.*, 2012; Hennessey, 2016), though evidence shows that organisation-focused changes and interventions can effectively reduce burnout among healthcare workers (De Simone, Vargas and Servillo, 2021). To address these issues, the standardisation of care pathways and improved inter-service communication have been recommended (Hogden *et al.*, 2017) and remain essential for reducing the stress associated with poorly coordinated care for patients, families, and the professionals supporting them.

The emotional toll for professionals exposed to repeated patient suffering, death and dying are well established in oncology and palliative care (Granek *et al.*, 2017; Dijxhoorn *et al.*, 2022). Previous research has identified the need for greater recognition of the emotional burden for professionals caring for people with terminal neurological diseases (Connolly, Galvin and Hardiman, 2015). Harris et al. (2018) found that professional well-being was almost completely ignored in the MND literature, despite alluding to stress and burnout as a problem. Similarly, this review found that professional well-being was not directly questioned or measured and was

not the primary aim of most identified sources. However, feelings of being overwhelmed, burdened, emotionally exhausted, frustrated, stressed, anxious and burnt-out were identified by professionals' managing different aspects of MND patient care. The psychological well-being of HCPs is a growing concern internationally (Vanhaecht *et al.*, 2021). Reduced professional well-being in many clinical areas, is linked to absenteeism, high rates of turnover and has implications for the quality of patient care (Williams, Rathert and Buttigieg, 2020). Phenomena, such as occupational stress, burnout, compassion fatigue and moral distress have been widely recognised for clinicians faced with prolonged exposure to patient suffering, complex end-of-life care dilemmas (Horn and Johnston, 2020; Pattison, Droney and Gruber, 2020) and for those working in high intensity clinical environments (Borges *et al.*, 2019; Kok *et al.*, 2023). The challenges described by professionals in this review further reinforce the need to investigate the well-being of this population, and to identify specific risk factors for reduced professional well-being in order to mitigate potential consequences for workforce retention and MND patient care.

It is important to highlight the positive experiences identified by professionals working with MND, including feelings of pride and satisfaction in being able to help (Hetzler, 2021) and enhanced appreciation for their own health and personal lives (Hennessey, 2016). Having good multidisciplinary team and collegial support was important for job satisfaction (Gamskjaer, Werlauff and Handberg, 2022); while for those who were working alone feelings of stress and anxiety were more prominent (Cipolletta and Reggiani, 2021; Phelps *et al.*, 2022). This is concordant with the palliative care literature, whereby homecare assistants and community nurses providing hospice care at home identify loneliness and isolation as factors negatively influencing their job satisfaction. While peer support and contact were factors that positively impacted their well-being and intention to stay in the role (Patynowska *et al.*, 2024)**.** Potentially protective or supportive factors were not explicitly measured in any identified source or explored with members of the multidisciplinary team, other than neurologists. Coping mechanisms, such as compartmentalisation and debriefing with colleagues were identified in one study (Hennessey, 2016). Previous

experience was helpful in certain circumstances (Olesen *et al.*, 2022), but was not always the case. More years of experience could in some circumstances be associated with higher stress levels (Bromberg, Schenkenberg and Brownell, 2011), and years of experience was not helpful in the most challenging clinical scenarios (Martin *et al.*, 2016; Chapman, Bayes and Sim, 2021). Personal protective factors, meaning in work (Moreno-Milan *et al.*, 2019) resilience (Zanatta, Maffoni and Giardini, 2020) and coping styles (Koh *et al.*, 2015; Kim and Kim, 2020) have been identified as supporting professionals working in palliative and other end-of-life care positions and warrant greater consideration for those working with MND.

This review identified that while professionals from different disciplines and working within different service and organisational structures share many of the same stresses, frustrations and emotional responses to working with this patient population, they also have different experiences, responsibilities and needs for support. Despite many sources recognising these differences, they were not explored in depth. To facilitate professionals to work synergistically and provide the level of integrated care required by MND patients, future work is needed to identify both the individual and shared needs for support of the different groups of professionals involved in providing care for these patients (Table 3.3).

## Study Strengths and Limitations

This is the first review to provide a comprehensive overview all HCPs' experience and perspective of providing MND care. The primary strength of this review is the use of a transparent, systematic, and reproducible search strategy and broad inclusion criteria.

Included sources were limited to the English language typically reflecting middle to high income countries such as the UK, USA and Australia. This may have excluded representation of healthcare services from other countries that may have provided alternative cultural insights or challenges. Some included sources can be considered low level evidence such as case reports and opinion pieces. Title and abstract screening were completed by the first author only. Although due care was taken,

some relevant sources may have been excluded in error, as they were not cross-checked. Critical appraisal of included sources was not undertaken; however, this was not relevant for the purpose of this review.

**What this review adds?**

• Motor neurone disease care can be experienced as intensive, distinctive and more time-sensitive than the care required by patients with other life limiting conditions.

• Professionals have experienced emotional exhaustion, burden, frustration, anxiety, stress and burnout due to caregiving for motor neurone disease patients and their families.

• The benefits of working with motor neurone disease are job satisfaction, receiving gratitude and enhanced appreciation for one's own personal life.

• External and organisational factors often perceived as outside of professionals control can limit their ability to provide desired levels of care, often resulting in feelings of stress and frustration.

• Multidisciplinary care is not only necessary to meet the multiple needs of patients and informal caregivers but is also an important source of emotional support for professionals working with motor neurone disease.

**Implications for practice, theory, policy or future research?**

• The emotional burden for professionals working with motor neurone disease patients and their families should be recognised. Future research should focus on directly addressing and measuring the psychological health and well-being of professionals involved in providing this care.

• The organisation of motor neurone disease patient services and processes for interservice communication and collaboration should be considered to reduce many of the external demands and associated stressors for professional care teams.

• Professionals working with motor neurone disease patients should have access to collegial and multidisciplinary team support, future work should consider what additional supports, interventions or training could help to reduce the professional stress and emotional toll associated with working with this complex condition.

• Future work should consider both the individual and shared needs for support of the different teams and professionals involved in providing motor neurone disease patient care.

**Table 3.3:** Summary of Key Findings from the Scoping Review and Implications for Practice and Research *Reproduced from Walls et al. (2024), pp. 1-2.*

## 3.5 Conclusion

By reviewing the literature available from 1990-2024, we have categorised how HCPs describe the experience of working with those affected by MND. Professionals perceive working with MND as distinctive from other life-limiting conditions. External and organisational barriers could limit their ability to provide optimal levels of care and working with these patients and families had implications for professional well-being. The potential for some to remain working in this clinical area over time was questioned, while others avoided working with this patient group. Working within an effective and supportive multidisciplinary team was important for both job satisfaction and emotional support. Addressing some of the external and organisational issues identified in this review has the potential to support and retain professionals to provide the intensive, integrated and specialist level of care required by these patients and their informal support network. It is also important to acknowledge and recognise the potential for professional stress and emotional burden for those interacting with these patients and their families. Future research should focus on identifying specific risk and protective factors for professional well-being and tailored support strategies to address the unique needs of professionals working with MND.

The next chapter (Chapter 4) presents the qualitative methods and findings from a focus group study of HCPs working across a number of key services involved in the delivery of MND patient care in Ireland. The study was designed to address several gaps in the existing literature identified from this scoping review and builds on some of the initial insights generated from this review.

# Chapter 4: Phase Two – Qualitative Focus Group Study

## A Reflexive Thematic Analysis of Healthcare Professionals' Experiences of Working with Motor Neurone Disease in Irish Healthcare Services


## Abstract

**Background:** The previous phase of this research outlines how the delivery of care for MND patients and families can present significant practical, ethical, emotional and psychological challenges for healthcare professionals. Despite the demands, many also describe it as deeply meaningful and fulfilling work. However, the current literature lacks a comprehensive understanding of what contributes to both the challenges and rewards of working with this population across the varied care settings and professional groups involved in delivering MND care.

**Aim:** To explore the experiences of a diverse group of healthcare professionals involved in providing MND care across Ireland. Specifically, this study seeks to examine the challenges and rewards these professionals associate with this role, the emotional and psychological impact of the work and the factors they perceive as helpful or supportive for them in their work with patients and families affected by MND.

**Design**: The focus group method was used to collect qualitative data from a purposive sample of healthcare professionals working across a number of key services for plwMND in Ireland. Demographic and work-related data were also gathered using a short questionnaire. Data were analysed using reflexive thematic analysis.

**Results**: Forty-two healthcare professionals participated in nine focus groups, representing multidisciplinary clinics, charity organisations, specialist palliative care, primary care, residential care and specialist seating and technology services. Four main themes were generated: (1) Navigating the relationship - trust and boundaries, (2) Working with uncertain certainty, (3) Helplessness – "*I can't fix this"* and (4) Managing the personal impact of working with MND. Subthemes are depicted within these.

**Conclusion:** This reflexive thematic analysis has illuminated the complex emotional and deeply relational landscape navigated by healthcare professionals responsible for providing MND care across all levels of the Irish healthcare system and throughout the MND patients care journey. Through exploring their experiences, it became evident that while clinicians are often deeply committed to providing compassionate and responsive care, they are also frequently challenged by feelings of uncertainty, emotional burden, helplessness and systemic constraints. The findings also offer suggestions for professional training, interpersonal support systems and organisational changes that may help to sustain professionals' ability to provide the level of compassionate and person-centred care required by this population.

## 4.1 Introduction

The scoping review undertaken in Phase One of this research outlines how the delivery of care for plwMND can present significant ethical, emotional and psychological challenges for HCPs (Walls *et al.*, 2024). Professionals working with this population are required to manage complex and rapidly changing clinical needs, while also guiding patients and families through the emotional and practical realities of progressive decline, increasing dependence, and end-of-life care (McConigley *et al.*, 2014). The cumulative exposure to patient suffering and the frequent confrontation with loss and death can contribute to emotional strain and psychological distress (Hennessey, 2016). In addition to the complexities of clinical care, HCPs must often navigate organisational constraints, resource limitations, and systemic pressures, all of which can heighten the demands of their work (Hogden *et al.*, 2011; Hennessey, 2016). Despite the challenges, HCPs have also described positive personal and professional experiences, emphasising the meaningful and rewarding aspects of supporting individuals and families living with MND, during a profoundly difficult period in their lives (Gamskjaer, Werlauff and Handberg, 2022).

Experiences of care, however, are not always positive from the perspective of patients and families. PlwMND have reported feeling "*let down*" by services, citing infrequent, uncoordinated care and poor communication with professionals as reasons for this (Aoun *et al.*, 2021). These negative experiences can lead to distress, frustration, and feelings of abandonment (Pinto *et al.*, 2021). In contrast, consistent, compassionate, and well-coordinated support from HCPs can reduce emotional distress, promote confidence in care, and help patients and families better cope with the progression of the condition (Pinto *et al.*, 2021). While the recent review by Walls *et al*. (2024) (Phase One: Scoping Review), identified several factors that can restrict professionals from meeting the needs of MND patients and their families, there is limited research that directly captures professionals' perspectives on the challenges they face, the barriers they navigate, and the factors that support their work. Moreover, the emotional engagement of HCPs with the MND patient–family dyad

remains underexplored, particularly how this involvement may affect their own well-being and consequently their ability to consistently deliver person-centred care.

Although a number of publications have acknowledged the emotional toll of working in MND care (Connolly, Galvin and Hardiman, 2015; Hennessey, 2016; de Carvalho Costa *et al.*, 2020; Beyermann *et al.*, 2023; Daneau *et al.*, 2023), few have considered the professional supports needed to protect staff well-being or enhance job satisfaction (Gamskjaer, Werlauff and Handberg, 2022; Hansen, Burton-MacLeod and Schellenberg, 2024). Gamskjaer, Werlauff and Handberg (2022) identified a number of key factors contributing to job satisfaction among professionals working with plwMND in an inpatient palliative rehabilitation setting. These included a sense of autonomy, professional purpose, skill mastery, strong collegial support, and a healthy integration of work and personal life. Participants reported that, when supported by a positive and appreciative work environment, caring for this patient group could be both enriching and professionally fulfilling. These findings provide some important insights; however, they are drawn from a single Danish inpatient rehabilitation setting and may not fully capture the experiences of professionals across the many other contexts in which professionals engage with MND patients and families. Overall, the literature lacks a comprehensive understanding of the factors that make working in MND care both challenging and rewarding, as well as the types of support needed by professionals across the diverse care settings involved.

Previous research shows that professionals vary widely in how they perceive and engage with MND care. Some report a deep sense of professional purpose and commitment (Hennessey, 2016), while others experience discomfort or avoidance, often due to the emotional demands or perceived complexity of the work (Lerum, Solbraekke and Frich, 2017). These differing responses may be shaped by factors such as individual resilience, training, team dynamics, and broader organisational support and culture. However, the conditions contributing to these variations remain poorly understood. Much of the literature to date has focused narrowly on specific clinical roles or situations, e.g. experiences of doctors delivering the diagnosis or withdrawing NIV (Faull, Haynes and Oliver, 2013; Lerum, Solbraekke and Frich, 2017; S. Aoun *et al.*, 2018), limiting a holistic understanding of the wider professional

experience. In the Irish healthcare system, care for people with MND is delivered through a combination of specialist and generalist services, with professionals varying in role, experience, and frequency of patient contact. These differences may shape the challenges encountered, the emotional impact of the work, and the kinds of support needed. A more nuanced understanding of professionals' experiences across settings is essential to inform how best to support each of the teams and services involved and to sustain high-quality care for plwMND and their families throughout all stages of their illness trajectory.

The aim of this study is to explore the experiences of a diverse group of HCPs involved in MND care across Ireland. Specifically, it seeks to examine the challenges and rewards they associate with this role, the emotional and psychological impact of the work and the factors they perceive as helpful or supportive for them when working with this population.

## 4.2 Methodology

This qualitative study was grounded in constructivist epistemology, which emphasises the co-construction of knowledge through participants shared experiences and interactions. Within this perspective, meaning is not objectively discovered but shaped by participants' social contexts (Guba and Lincon, 1994). This study sought to explore the subjective experiences of HCPs working with individuals and families affected by MND using focus groups to facilitate rich interaction, dialogue, and collaborative exploration of perspectives across diverse professional backgrounds (Freeman, 2006). This approach was considered particularly valuable for this study to capture both shared understandings and different perspectives shaped by professional role, health care setting and team dynamics (Ivanoff and Hultberg, 2006). Nine focus groups with multidisciplinary professionals involved in MND care from various settings in Ireland were facilitated. The data were analysed using reflexive thematic analysis, a method that is well-suited to examining patterns of meaning within complex datasets while recognising the active role of the researcher in developing and interpreting themes (Braun and Clarke, 2019).

### Ethical Approval

Ethical approval was obtained from the School of Medicine Research Ethics Committee, in Trinity College Dublin on the 31.05.23 (Application Number: REAMS: 2551). Ethical approval was also obtained from local ethics committees as required for participating sites. See Appendix E for the ethical approval confirmation letters.

### Data Protection

In advance of data collection, a Data Protection Risk Assessment and Data Protection Impact Assessment were completed. These were reviewed and approved by the Data Protection Officer (DPO) in Trinity College Dublin on the 30.08.23. A Joint Control Agreement between London South Bank University (LSBU) (location of co-supervisor) and Trinity College Dublin (TCD) was in place to facilitate data sharing for this study.

## 4.2.1 Sampling and Recruitment

### Sampling Technique

Purposive maximum variation sampling was used to recruit participants for the focus groups. Purposeful sampling is widely used to identify participants in qualitative research (Campbell *et al.*, 2020), participants in this study were purposively selected due to their recent experience of working with plwMND in Ireland. To align with the study's objectives, we also purposively recruited for variation in profession and healthcare setting to capture a broad spectrum of experiences and perspectives across the focus groups.

Snowball sampling, whereby initial participants are asked to identify others who meet the inclusion criteria but may not be easily accessible to the researcher (Naderifar, Goli and Ghaljaie, 2017; Parker, Scott and Geddes, 2019), was used to recruit HCPs working in primary care. Because many primary care professionals may encounter only a single patient with MND in their career (Lerum, Solbraekke and Frich, 2017), this method allowed the researcher to identify clinicians with recent and relevant

experience of working with people living with the condition. Participants recruited from MND specialist services were asked to identify colleagues in primary care who met the study criteria and to share the study information with them.

### Sample Size Determination

Sample size in qualitative research has long been the subject of scholarly debate (Blaikie, 2018; Ahmed, 2025). Traditionally, the concept of data saturation, defined as the point at which no new codes or themes emerge, has been upheld as the gold standard for determining purposive sample adequacy (Guest, Bunce and Johnson, 2006). However, there is little consensus about how and when saturation is achieved (Hennink, Kaiser and Marconi, 2017; Nelson, 2017; Saunders *et al.*, 2018), and its applicability remains contested (Jennings and Yeager, 2025). While proponents argue that saturation ensures comprehensiveness, others contend that the complexity and nuance of human experience make complete saturation elusive, as new insights may always arise with additional data (Braun and Clarke, 2021). In response, many qualitative researchers now advocate for a more flexible and transparent approach, prioritising the richness, relevance, and diversity of data over strict adherence to saturation benchmarks (Malterud, Siersma and Guassora, 2016; LaDonna, Artino and Balmer, 2021; Naeem *et al.*, 2024). In alignment with these perspectives, this study adopted a context-specific and pragmatic approach to determining sample size, informed by the research purpose, methodological framework, and characteristics of the participant group (Mwita, 2022).

In reflexive thematic analysis, the notion of saturation is viewed as conceptually incompatible with an interpretivist stance, where meaning is understood as constructed through interaction rather than objectively discovered (Braun and Clarke, 2021). Accordingly, this study did not seek a fixed numerical endpoint or thematic redundancy but instead drew on the principle of information power (Malterud, Siersma and Guassora, 2016). Data adequacy was assessed in terms of the richness and relevance of insights in addressing the research aim, with emphasis on interpretive meaning-making rather than thematic exhaustion.

The number of focus groups conducted was informed by the decision to stratify participants by healthcare setting. A key objective was to ensure representation from all major services involved in the delivery of MND care in Ireland. Within each group, diversity was also a priority, and efforts were made to include professionals from multiple disciplines. However, recruitment was pragmatically shaped by the composition and size of the multidisciplinary team, as well as the number of eligible participants within each service. For example, MND specific charity organisations employ only nurses, resulting in a less diverse focus group in that setting. Finally, group size was guided by existing recommendations for focus groups of 4–12 participants, small enough to enable meaningful contribution yet large enough to capture diverse perspectives (Onwuegbuzie *et al.*, 2009; Fusch *et al.*, 2022). This approach balanced representational breadth with the practicalities of recruitment and facilitation.

### Recruitment Process

- Key services involved in the provision of care for plwMND and their families were contacted by the lead researcher and provided with the study protocol to determine their interest in participating. Services that expressed interest appointed a gatekeeper to facilitate participant recruitment.
- The lead researcher met individually with each gatekeeper to explain the purpose of the study, outline the inclusion criteria (Table 4.1) and provide study information leaflets. Gatekeepers then disseminated this information to eligible staff members within their respective services.
- Interested individuals contacted the lead researcher directly via email to express interest in participating. The lead researcher responded to all enquiries, provided additional details about the study, and answered any questions. To ensure informed decision-making, all potential participants were given a minimum of one week to consider their involvement.
- Following confirmation of interest, the lead researcher coordinated with the relevant gatekeeper to schedule the focus group at a time convenient for

participants. The agreed date and time were then communicated to all confirmed participants.

- For online focus groups, participants received the participant information leaflet, consent form, demographic questionnaire, and a secure meeting link via email 1–3 days before the scheduled session. For in-person focus groups, participants were emailed a meeting reminder along with the participant information leaflet, consent form, and demographic questionnaire within the same timeframe.
- All participants were required to provide written informed consent before participating in the study. For online groups, signed consent forms were returned via email prior to the session. For in-person groups, participants submitted their signed forms on the day of the focus group. Completed demographic questionnaires were collected at the same time.

**Table 4.1:** Inclusion and Exclusion Criteria Applied for Participant Selection

| **Inclusion Criteria** | **Exclusion Criteria** |
|---|---|
| Healthcare professionals (HCP) currently or previously employed to provide care or services to individuals living with MND. | Those not employed as a healthcare professional (e.g., volunteers, informal carers, or administrative staff). |
| Have worked in a healthcare service that provides care to people with MND within the past 24 months. | Have not worked in a healthcare service providing care to individuals with MND in the past 24 months. |
| Have direct experience of providing care or support to at least one individual with MND in the past 24 months. | Have not had direct experience working with at least one individual living with MND in the past 24 months. |

### 4.2.2 Dataset Generation: Focus Group Method

#### Rationale for Focus Group Method

Focus groups are particularly valuable for exploring how professional roles, team dynamics, and organisational contexts influence individual and collective experiences (Flynn, Albrecht and Scott, 2018). This approach helps uncover both

shared experiences and points of divergence that may not emerge in individual interviews or other methods of qualitative data collection (Gill *et al.*, 2008). Additionally, the group setting fosters an environment where participants can build upon each other's insights, resulting in a more nuanced understanding of the research topic (Krueger, 2014). Given the relational and collaborative nature of multidisciplinary MND care, focus groups provided an interactive approach that was especially effective in eliciting practice-based reflections and capturing the complexities of working within diverse teams and healthcare structures.

### Topic Guide and Question Development

The topic guide developed for the focus groups was primarily informed by gaps in knowledge identified in the preceding scoping review (Phase One), ensuring that discussion topics addressed areas underexplored in the existing literature.

A broad *discussion starter question* was used to initiate the conversation. This question was designed to be easy to answer, encourage participation from each group member and support participants to begin thinking about their own thoughts, perceptions, and experiences on the topic (Morgan, 2019). Follow-up questions addressed five core areas: barriers and facilitators to providing care for plwMND and their families; aspects of the role professionals find most challenging or stressful; elements they find most rewarding; and the personal or professional characteristics perceived as helpful and protective. Probing questions and cues were included for each core question. The final *wrap-up* question provided participants an opportunity to share any additional insights that hadn't been discussed (Morgan, 2019) (See full topic guide in Appendix F).

### Expert Opinion

The initial draft of the topic guide was reviewed by an Occupational Therapist, a Speech and Language Therapist, and a Psychologist, all working in specialist MND roles. Their feedback was used to refine the structure and content, and all suggested amendments were incorporated into the final version.

### Pilot Testing

The revised topic guide was pilot tested in two focus groups, one conducted online and the other in person, with participants from a palliative care service and a specialist MND service. The purpose of the pilot was to evaluate the clarity and flow of the questions, as well as the overall facilitation process, and to gather feedback that informed final refinements before full data collection.

### Focus Group Facilitation

Focus groups were facilitated both online and in-person, to enable convenient participation for all groups and services. All focus groups were facilitated by the lead researcher (MW). Traditionally, focus groups have been carried out in a face-to-face modality however, logistical challenges such as arranging a suitable location can often restrict effective participation (Rolls *et al.*, 2016). When participants expressed a preference for face-to-face meetings, the focus group was held at their workplace, where possible. While some argue that in-person focus groups foster better interaction and information sharing, several studies have demonstrated that online focus groups can generate similarly rich qualitative data, particularly with HCP participants (Matthews, Baird and Duchesne, 2018; Guest *et al.*, 2020; Jones *et al.*, 2022; Chai *et al.*, 2024).

Previous research suggests that online participation fosters lower commitment compared to in-person meetings (Tuttas, 2015; Matthews, Baird and Duchesne, 2018). For this study, the lead researcher worked closely with gatekeepers to schedule focus groups at convenient times and sent calendar invitations and reminders 1–3 days before the meeting to minimise dropouts. Technical difficulties, connectivity issues, poor sound quality, and weak internet connections, can also affect the quality and reliability of data in online focus groups (Lobe, Morgan and Hoffman, 2022). Tuttas (2015) found that having an assistant moderator for technical support reduced challenges, while Matthews, Baird and Duchesne (2018) highlighted that the moderator's proficiency in using the software was crucial for successful data collection. To mitigate technological issues, the lead researcher developed

proficiency with Microsoft Teams software and created a step-by-step guide for participants on how to join and engage in virtual focus groups (Appendix G). Co-moderators were trained to assist with technical support, and participants were offered a trial session to address any concerns before the meeting. For in-person focus groups, videoconferencing software was pre-tested ahead of the scheduled meeting.

### 4.2.3 Data Analysis

#### Transcription and Data Management

In-person and online focus groups were audio and video recorded and transcribed using Microsoft Teams software automated transcription feature (Microsoft, 2024). The written transcripts were pseudo-anonymised to protect participant confidentiality, identifiable details such as the participants name or the name of their workplace, were replaced with unique codes. The lead researcher carefully cleaned the transcripts by correcting minor transcription errors and cross-checking them against the audio and video recordings to ensure accuracy and completeness before being finalised for analysis. The cleaned transcripts were uploaded to NVivo 12 (QSR International, 2024) for coding, sorting, and collation of the data.

#### Reflexive Thematic Analysis

Reflexive Thematic Analysis (RTA) is an accessible and theoretically flexible approach to qualitative data analysis (Braun and Clarke, 2006, 2019, 2021). It enables the identification and interpretation of patterns or themes within a data set, offering a robust method for extracting meaningful insights across qualitative data (Braun and Clarke, 2019). RTA offers an approach that encourages the researcher to be actively engaged in interpreting the data through their own lens, acknowledging how their perspectives, experiences, and positionality influence the analysis (Braun and Clarke, 2019). This method allows for a rich, nuanced understanding of the data while recognising the subjectivity involved in qualitative inquiry. Given that the lead

researcher's knowledge and professional experience with the research topic is considered a valuable resource in this study, using a reflexive approach ensured a transparent, rigorous, and meaningful analysis.

Braun and Clarke (2006, 2019) provide a six-step process for conducting RTA and this was followed during data analysis. Although these steps are presented sequentially (Table 4.2), the analysis was recursive and involved an iterative process of moving back and forth between phases (Braun and Clarke, 2019). A detailed process log was maintained throughout, that documented key insights, emerging thoughts and decision making (Appendix H).

**Table 4.2:** Reflexive Thematic Analysis Process Followed in This Study

| |
|---|
| 1. **Familiarisation with the dataset**: Data transcripts were read and re-read, for the researcher to become immersed and familiar with the content. Initial impressions, analytic observations, and potential patterns were noted reflexively to support the development of a nuanced understanding of the data. |
| 2. **Coding**: Transcripts were open coded to best represent the experiences as described by participants; elements of deductive coding were however also required to ensure that the codes developed addressed the aim of the study and supported the objective of informing the subsequent quantitative phase of this research. MW read and re-read the transcripts and made comments that informed the development of the initial codes. NVivo qualitative data management software (QSR International, 2024) was then used to develop and sort the codes created. Coding was predominantly data-driven, using both semantic and latent coding techniques. Items of data were double coded as relevant reflecting the explicit meaning communicated by the participant and the implicit meaning interpreted by the researcher. This approach is congruent with the constructivist epistemological standpoint, whereby the meaning constructed by the participant and the researcher's interpretation of this meaning are both considered and represented (Byrne, 2022). This process was iterative, and transcripts were revised many times for examples when new codes or meanings were identified. |
| 3. **Generating initial themes:** The codes and supporting data were examined, mapped and sorted to develop broader patterns of meaning. Supporting quotes and statements were collated relevant to each potential theme. |

| |
|---|
| 4. **Developing and reviewing themes:** Candidate themes were developed through an iterative and interpretive process, shaped by the researcher's engagement with the data and analytical lens. Themes were reviewed and refined in relation to the coded data and the broader dataset to ensure they captured shared patterns of meaning and provided a coherent and meaningful response to the aim of the study. |
| 5. **Refining, defining, and naming themes**: A detailed analysis was conducted for each theme, supported by key participant statements and illustrative quotations. Theme names were carefully reviewed to ensure they not only captured the essence of the data but also engaged the reader's attention and clearly conveyed the central ideas within each theme and its sub-themes. |
| 6. **Writing up:** An analytical narrative of the data was produced and contextualised in relation to existing literature. |

### Researchers Position

MW is an Occupational Therapist with experience of working with plwMND in one of the largest specialist palliative care services in Ireland. At the time of data collection MW was also affiliated with the Academic Unit of Neurology (AUoN), the largest research group for MND research in Ireland. With approximately 400 plwMND at any one time, there are a limited number of HCPs working in MND specialist roles in Ireland. The close affiliation of the AUoN research group with the national clinical centre for MND and the MND charity organisation in Ireland, resulted in some focus group participants being aware of MW's position, despite this not being explicitly disclosed during data collection. Reflexive practices were implemented (outlined below), acknowledging the influence of MW's position as a clinician-researcher on the data collection and analysis process.

### Reflexivity

Reflexivity is a critical component of qualitative research, requiring researchers to continually reflect on their own positionality, assumptions, and potential biases throughout the research process. As defined by Olmos-Vega *et al.* (2023) reflexivity is:

"*a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes"* (Olmos-Vega *et al.*, 2023, p.241).

Reflexive practice enhances trustworthiness and credibility, by making the role and impact of the researcher transparent and acknowledging that complete objectivity is neither possible nor desirable in qualitative inquiry (Darawsheh, 2014; Rettke *et al.*, 2018).

Personal reflexivity was an important aspect of this study as the lead researcher (MW), is a clinician-researcher, with experience of working in this clinical area. In this study, reflexivity involved an ongoing awareness of how the lead researcher's professional background, personal & professional experiences, and clinical values could influence the design, data collection, interpretation, and presentation of findings (Berger, 2015). Continuous self-reflection throughout the research process was essential to minimise the potential influence of the researcher's biases or preconceptions (Palaganas *et al.*, 2017). However, the dual role of clinician and researcher also offered notable strengths. The researcher's familiarity with the clinical setting, shared professional language, and contextual understanding, was felt to contribute to the generation of clinically relevant insights and the effective dissemination of findings.

Personal reflexivity extends beyond simply disclosing a researcher's background or training, it involves actively considering how prior motivations, experiences, and interests may shape decisions throughout the research process (Olmos-Vega *et al.*, 2023). Reflexive writing is one approach to engaging in such practice (Watt, 2007). Prior to data collection, the lead researcher recorded and transcribed a personal interview, reflecting on their own experience of working with individuals and families affected by MND within a palliative care context. During data analysis, this interview was revisited and considered alongside the participant data. The researcher reflected critically on areas of convergence and divergence between their own perspectives and those shared by participants. This process supported greater

awareness of how the researcher's clinical experience and assumptions might influence the interpretation of data.

Throughout the data collection process, the lead researcher maintained a detailed reflexive and process log (Meyer and Willis, 2019), which was updated after each focus group. The log captured reflections on facilitation style, questioning techniques, and researcher positioning, as well as contextual and interpersonal factors that may have influenced the depth or quality of the data, such as technical challenges or group dynamics. All key decisions were documented and justified. This ongoing reflexive practice enhanced self-awareness and enabled the researcher to critically examine how their role and interactions may have shaped the collection, interpretation, and understanding of the data (Koopman, Watling and LaDonna, 2020).

The second approach to reflexive practice centred around collaboration (Olmos-Vega *et al.*, 2023). Collaborative reflexivity acknowledges that the research team often rely on each other to ask difficult questions about assumptions and decision making (Berger, 2015). The research team met regularly thought each phase of this study. The supervisory team played a crucial role in challenging the lead researcher's prior assumptions, justifying key decisions, and ensuring the accurate and rigorous interpretation of the data. Their external perspectives encouraged the lead researcher to consider alternative viewpoints and highlighted aspects of the data that might otherwise have been overlooked.

### Reporting

This study is reported in line with the Reflexive Thematic Analysis Reporting Guidelines (RTARG) (Appendix I) (Braun and Clarke, 2024).

## 4.3 Results

### 4.3.1 Participants

Nine focus groups, with 42 participants took place between September 2023 and May 2024. Four were facilitated online, four in-person and one was a hybrid model, where two participants and the researcher were in-person, and one participant attended online. The focus groups lasted for an average of 53 minutes (range: 45-69). The duration of online and in-person focus groups was similar, averaging 49 and 56 minutes, respectively.

Those who attended the focus groups were from ten different professions, across six targeted settings: palliative care (*n* = 14, 33%), multidisciplinary MND clinics (*n* = 12, 29%), assistive technology and specialist seating services (ATSS) (*n* = 3, 7%), MND charity organisations (*n* = 5, 12%), primary care (*n* = 4, 9.5%) and residential care (*n* = 4, 9.5%). The majority of participants were female (88%) and nurses (34%). For over half of those who participated (52%), plwMND made up only 0-25% of their overall caseload, while for 41% of participants more than 50% of their clinical caseload were plwMND. Those working in multidisciplinary clinics[1], MND charity organisations and the ATSS clinic interacted with 15-53 plwMND per month, while those working in primary care, palliative care and residential care, interacted with 2-3 plwMND per month. See full demographic details in Table 4.3.

[1] One of the included MND MDT clinics (FG 6 in Table 4.3) operated on a monthly basis, with an average caseload of 15 MND patients per month. In contrast, the other included MND MDT clinic (FG 1 & 6 in Table 4.3) operated on a weekly basis, resulting in a substantially higher monthly patient contact rate (30-53) for these participants.

| **Focus Group** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Setting** | Multi-disciplinary Clinic* | Palliative care* | Residential Care | MND Charity Organisation | Palliative Care | Multi-disciplinary Clinic | Primary Care | ATSS Service | Multi-disciplinary Clinic | | |
| **Mode** | Online | In-person | In-person | Online | In-person | Online | Online | Hybrid | In-person | **Total** | |
| | *n* | *n* | *n* | *n* | *n* | *n* | *n* | *n* | *n* | *n* | % |
| **Number of participants** | 3 | 7 | 4 | 5 | 7 | 4 | 4 | 3 | 5 | 42 | |
| **Gender** | | | | | | | | | | | |
| Male: | 0 | 2 | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 5 | 12 |
| Female: | 3 | 5 | 2 | 5 | 6 | 4 | 4 | 3 | 5 | 37 | 88 |
| **Profession** | | | | | | | | | | | |
| Doctor: | 1 | | | | | | | | | 1 | 2 |
| Occupational Therapist: | 1 | 1 | 1 | | 2 | | 1 | 1 | | 7 | 17 |
| Speech Therapist | 1 | | | | | 1 | 2 | 2 | | 6 | 14 |
| Physiotherapist: | | 1 | 1 | | | 2 | | | | 4 | 10 |
| Nurse: | | 2 | 1 | 5 | 4 | 1 | | | 1 | 14 | 34 |
| Social Worker: | | 1 | | | 1 | | | | | 2 | 5 |
| Psychologist: | | 1 | | | | | | | 3 | 4 | 10 |
| Complimentary Therapist: | | 1 | | | | | | | | 1 | 2 |
| Healthcare Chaplain: | | | 1 | | | | | | | 1 | 2 |
| Dietitian: | | | | | | | 1 | | 1 | 2 | 5 |
| **Percentage of caseload MND** | | | | | | | | | | | |
| 0-25% | | 6 | 3 | | 6 | 3 | 3 | 1 | | 22 | 52 |
| 26-50% | 1 | | 1 | | 1 | | | | | 3 | 7 |
| 50-75% | 2 | 1 | | | | | 1 | 2 | 1 | 7 | 17 |
| 76-100% | | | | 5 | | 1 | | | 4 | 10 | 24 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Average monthly MND caseload** | 53 | 2.5 | 2 | 30 | 3 | 15 | 2 | 15 | 30 | - | - |
| **Average years of MND experience** | 9 | 8.5 | 6 | 11 | 12 | 5 | 15 | 10 | 6.2 | - | - |
| **Average years of professional experience** | 13 | 14 | 12 | 26 | 22 | 17 | 20.5 | 14 | 12 | - | - |

**Table 4.3**: Focus Group Participants Demographic Data.

*Pilot online and in person focus groups, focus groups 1 & 6 = monthly MND MDT clinic**,** focus group 9 = weekly MND MDT clinic.

**Table 4.4**: Abbreviation Key for Professional Roles and Services in Participant Quotations

| **Profession** | **Abbreviation** | **Service** | **Abbreviation** |
|---|---|---|---|
| Doctor | Doc | Palliative Care | Pall Care |
| Occupational Therapist | OT | Primary Care | Prim Care |
| Speech and Language Therapist | SLT | MND Multidisciplinary Outpatient Clinic | MDT Clinic |
| Physiotherapist | PT | Residential Care | Res Care |
| Nurse | Nurse | Assistive Technology & Specialist Seating Service | ATSS |
| Medical Social Worker | MSW | MND Charity Organisation | Charity |
| Psychologist | Psych | | |
| Complimentary Therapist | Comp Therapist | | |
| Healthcare Chaplain | Chaplain | | |
| Dietitian | Dietitian | | |

### 4.3.2 The Analysis

Four distinct themes were generated from the reflexive thematic analysis (RTA), each of these themes were identified across the data from each of the represented services. The thematic map in Figure 4.1 (displayed at the end of this results section) illustrates these themes, the related sub-themes and demonstrates the relationships and connections between them. Braun and Clarke (2024), advise, when using RTA, that themes should connect in a logical and meaningful manner and build a condensed narrative of the data. Where relevant themes should build upon previously reported themes, while remaining internally consistent and capable of communicating their own individual narrative if isolated from the other themes.

The four themes developed through the analysis reflect distinct yet interconnected aspects of HCPs' experiences of supporting patients and families throughout the MND care journey. They are presented below in a sequential trajectory from the formation of professional relationships, through uncertainty surrounding care planning, to the sense of helplessness experienced when solutions feel difficult to implement or appear futile. These themes converge in the final theme, which explores how professionals manage the personal and emotional toll of working in this challenging field and highlights strategies currently used to remain engaged, motivated, and committed to this work.

## 4.3.2.1 Theme 1: Navigating the Relationship – Trust and Boundaries

#### The depth of the relationship

Participants across all services described the depth of the relationships they often formed with plwMND and their families. The therapeutic relationship was identified as unique and different to other conditions they had worked with, and was commonly attributed to frequent interactions, and the intensity of care provided over the course of the illness.

*You build a rapport that's I suppose unique to the clinic... more so than I think other hospital based clinics, where it would be more kind of matter of fact, you know, how's the diabetes and out you go... so it's we see them at such frequency... it's every 6 to 8 weeks, 12 weeks so we see them so frequently that I think you kind of, you nearly have to build a rapport...you learn so much about each other.* (Doc, MDT Clinic)

The importance of establishing a trusting therapeutic relationship was emphasised as the foundation for providing the holistic and person-centred care plwMND require, *'...you have to have built up a relationship with them, so that you can piece [together], what they want and need...'* (Nurse, Charity). The focus on holistic care and quality of life additionally meant that participants came to know detailed aspects of a person's life, including their interests, values, and family dynamics. This could create a sense of being intensely involved in their life or '*on the disease journey'* with them and some experienced how this intensified the emotional difficulty as the patient's condition deteriorated, they passed away or were no longer able to engage with a service.

*I think because you get, you really get to know the person and as I say, because its such quality of life, you get to know what their interests are, about their family, about their life. I think that can be emotionally difficult, then as things, as challenges arise.* (OT, MDT Clinic)

However, the depth of the relationships they formed were also acknowledged as one of the most rewarding aspects of working with this cohort of patients and their families, '*it is rewarding, believe or not, to be on the journey completely with them'*. (Nurse, MDT Clinic)

*... you're very emotionally invested, so there is a drain on you, but there is a, there's a depth and a warmth to it as well and that's very rewarding.* (SLT, Prim Care)

## Personal resonance and emotional connections

Across all services, participants frequently related patients' circumstances to their own lives, imagining themselves or their loved ones in similar situations, and acknowledged how deeply confronting these reflections could be. '*I think, Oh God, I would be terrified, and I would probably be very, very, very, very anxious and I'm in admiration of some people who have gone through that terrible suffering',* (Nurse, Pall Care). For some, this resonance provided valuable perspective, while others felt it necessary to maintain personal and emotional distance. They consciously avoided imagining themselves in the patient's situation, finding the nature of the disease too emotionally challenging, and viewed that a level of detachment was necessary in sustaining their ability to provide care.

> *We all put ourselves in a situation, and think, what would I do if I had that, and I tell you what, I try not to do that with [MND], because then a bit like yourself (OT) I would find it very difficult going in at times*. (Nurse, Palliative Care)

Several participants identified individuals affected by the condition who stuck a personal cord or resonated with their own life in some way, '*Then it's those moments… when it resonates with you for a personal reason, then you kind of take a step back and it becomes a more personal I think…'*(SLT, ATSS). From an emotional perspective these were identified as some the most challenging cases for some participants to work with, '*I think the ones I find most challenging are kind of ones that you can, they're kind of similar to your life or your own experiences… I find them very difficult, for myself to deal with'* (Nurse, Charity).

> *I think when I initially started here there was just a lot of farmers like my Dad, you know, and they're the ones that would really trigger, you know, the people that you can relate so closely to family members…* (OT, ATSS)

> *…or for me, it's people, with kids, similar age to mine, where you're like, I know what this life is like and you're thinking like for everyone, I think there's a thing isn't there.* (SLT, ATSS)

Heightened feelings were also described towards people with challenging social circumstances, that made living with the condition even more difficult for them.

> *...and for those people who maybe have very little family support and who maybe aren't married or maybe widowed, or don't have any kids, maybe it's just themselves and their husband, but they're quite elderly or something like that... they would be the ones that probably pull on my heart strings a bit more and that kind of go a bit, kind of, that extra bit for them.* (Nurse, Charity)

Participants also described the emotional strain experienced from witnessing the impact of this condition on the family or wider social circle and the profound sense of loss and grief they experienced, not only for their loved one, but also for the life they had envisioned together.

> *I find it quite hard if I have to see them at home and because you see a picture of like what their life looked like and... actually I personally... find the, the partner quite upsetting more than the person with MND... you know, the man... his wife is the lady I think about a lot... they met each other really late in life and it was their second marriage and shortly after they got married, he was diagnosed... they had this whole exciting piece of what their life would look like and you go into their house and you can see really clearly, that's what they expected...and their life isn't like that... she's his full-time carer... and so he was one I cried over and I remember him very distinctly.* (SLT, ATSS)

The personal connections professionals formed with patients and families, and the depth of these relationships, often evoked strong empathetic responses, of wanting to give '*a bit extra'* or '*go that extra mile for a patient and for a family...*' (Nurse, Charity).

> *There will always be those families that you have just more of an emotional connection with than others, and I think that is what we end up doing, we kind of channel it into, they're the people we champion, you know.* (SLT, ATSS)

However, these relationships could also at times blur boundaries for participants, creating a grey area between their personal empathy and professional responsibilities.

> *I don't feel that I always get it right in making the decision, but I very rarely go to funerals… maybe three in my entire ten years, but there's times when I've done it and I felt maybe I shouldn't have, and there's times that I haven't done it but felt I really should have, you know, that kind of way*. (Nurse, MDT Clinic)

## Navigating trust and boundaries in the patient-clinician relationship

The emotionally charged nature of patient situations, combined with the intensity of clinician involvement in caring for plwMND, could create dilemmas in maintaining clear professional boundaries. Participants frequently described a tension between the compassionate pull to do their utmost for patients and a push back from the practical constraints of what could realistically be delivered within the scope, boundaries, and limits of their professional roles. '*…this is very difficult especially because we have such a sense of… wanting to meet their needs, and sometimes you just can't and when you can't it's so upsetting*' (Nurse, Pall Care).

> *So that, that is the really challenging piece emotionally, I think for us as professionals to kind of realise what you could be doing for someone and what you're able to do for someone and trying to, you know, just make your peace with that huge gap that exists sometimes, is really the tricky piece… feeling like I can't do anything and wishing I was able to do more…* (SLT, ATSS)

Participants described how often their inability to meet the needs or expectations of patients and families could strain the therapeutic relationship and erode previously established trust, "*…if you're not providing, you know, kind of concrete solutions… sometimes it feels like the patient loses a bit of trust in you, and then ultimately that becomes a real barrier to try… carry out your kind of duty of care*" (PT, Pall Care). Although many of these barriers arose from factors beyond their control, such as unavoidable disease progression, resource constraints, or role limitations,

professionals often felt pressure to extend their boundaries to address unmet needs and to avoid feelings of guilt, inadequacy, or having let the person down.

> *We've no speech and language therapist and it comes back on us to try and randomly come up with stuff that we're not trained in, in trying to desperately get a communication [aid], some sort of device for those people, and that's really stressful because we're not qualified in it at all and you can't get help on the outside, because there's nobody in [the community post]; so, it's either you don't do anything, or you try your best and you don't even know if it's the right thing, you know*. (OT, Pall Care)

Despite their best efforts, participants sometimes became the target of patients' or families' anger and frustration, often stemming from perceived shortcomings and inefficiencies within the health and social care system. While they recognised that these emotions were not personally directed, being the visible face of a system unable to consistently meet patient and family needs was often demoralising and could undermine their sense of professional integrity and trustworthiness.

> *So there's sometimes just these delays that are totally out of your control... but as far as the family are concerned, you're the person that's responsible for getting them this piece of equipment... so, I think you can change your relationship with the family because they don't always see that was out of your control, that that was a funding issue with the (health service)... and I think that's really difficult just to kind of rationalise for the family in a way that doesn't make it feel like you've let them down*. (SLT, ATSS)

Participants also described how conflicts could emerge within the therapeutic relationship when they were tasked with conveying difficult truths or implementing care plans that reinforced the reality of an incurable, progressive condition.

> *The anger can be, I think directed towards... frustration and anger towards the staff, but it's not it's not really about the staff, but we have to hold that, say, well, this isn't really about us you know, that this anger is about the whole situation...* (Nurse, Res Care)

Transparent, open, and honest communication was seen as essential for sustaining trust and collaboration in the therapeutic relationship. It allowed professionals to manage patients' and families' expectations regarding issues such as the availability and suitability of treatments and interventions, achievable outcomes, the level of care that could realistically be provided, and the roles and responsibilities of the clinicians and services involved ...*some people think, can you not be here on a weekly basis? and it is managing people's expectations... because there are only six of us*. (Nurse, Charity)

> *It's just management of expectations and being really transparent with people around the role of our service, the limitations of it and the timelines for getting things in place, because that's often where things break down*. (SLT, ATSS)

While trust within the therapeutic relationship was acknowledged as essential, it was also recognised as dynamic and evolving over time. Participants recognised how initially they often needed to *work hard* to earn the trust of both patients and their family members, '*sometimes there can be resistance and it takes a while to build up a trusting relationship between us and the family*' (Nurse, Pall Care). As the condition progressed, sustaining this trust often became increasingly challenging, not only because of systemic constraints but also due to changes in interpersonal dynamics associated with condition-specific factors such as cognitive or behavioural changes, communication impairments, and difficulties with psychological adjustment.

One Occupational Therapist reflected on the challenges of navigating behavioural changes in a patient with whom they had developed a strong therapeutic alliance and the impact of this both for them personally and on team dynamics.

> *...there's definitely been a change [in behaviour] and that can be really hard when you're working with someone for four years and they present a certain way and then they suddenly change... sometimes it can come across as almost personal... maybe disliking certain team members*. (OT, Res Care)

Given the critical role of the entire multidisciplinary team, care delivery was described as considerably more challenging when trust in particular members of the team was compromised. Participants described instances where patients or families placed their confidence in, or allowed involvement from, only selected professionals, '*...In terms of physio, we have been through a couple of different physios now where we've been told, "I don't want to see her again"'* (PT, Res Care). These dynamics could place additional pressure on individual clinicians and disrupt team cohesion, as *'trusted'* professionals often assumed disproportionate responsibility while others struggled to meaningfully engage or contribute to care. As patient needs intensified, sustaining these selective relationships and meeting intensifying care needs became increasingly challenging, and were recognised as placing some team members at heightened risk of physical and emotional strain and, in some cases, burnout.

> *If you are the person that has the trust, particularly when those behavioural issues start creeping in, I find that there is sometimes there is a very select few that multiple things start falling on a huge amount of time, which again just leads to a huge amount of [professional] burnout...*
>
> *...and it's, I find it's difficult within a team situation to be able to, as someone who's not on the trusted side, to be able to support the other members of the team who are and then vice versa .., it can make it very difficult in team dynamics.* (Nurse, Pall care)

When faced with complex clinical situations, participants emphasised the need to set aside their personal emotions to remain objective in their reasoning and decision-making. Some described consciously managing the relationships they formed by maintaining emotional distance and setting personal boundaries to avoid becoming '*drawn into their emotional journey'*.

*I guess you to have that boundary, and you know, be empathetic but try and not to take that home and it's not because you don't acknowledge that, it's just because you have to have some boundary, to do your job and to do what you can for the people that you're seeing.* (OT, ATSS)

Striking a balance between building a therapeutic relationship based on trust, empathy, and rapport, while managing personal emotional responses, was viewed as essential both for delivering safe, effective care and for safeguarding professionals' well-being. However, as one psychologist reflected maintaining this balance over the often lengthy, evolving and emotive course of an MND patient's journey, within a complex healthcare system, without distancing oneself could be challenging to effectively achieve.

*To stick with it and to have the inner resources to actually process all of what we're talking about is really, really hard and complex, and every person will throw up different things for you, but yet to have that and to just sometimes, we have to hold that long enough throughout the course of the illness, like which can be quite long in some cases, years in some cases you know, so to have the emotional stamina you know to stick with it and not distance yourself from it, is really hard.* (Psych, Pall Care)

### 4.3.2.2 Theme 2: Working with Uncertain Certainty

#### Anticipatory Stress

Participants described experiencing stress and anxiety related to anticipated future changes or potentially challenging situations that may or may not occur. Some reported feelings of anticipatory stress even before meeting a person with MND and their family, or ahead of specific interactions. This anxiety was driven by concerns

about the potential complexity of the situation, the likely emotional demands involved, and the many condition-related factors that could change and influence the patient's disease journey.

> *I think as well for us sometimes as practitioners, you know, you do feel a sense of anxiety a little bit of, kind of, you know panic in a sense, even initially before you know going into the person… because each family that has a person there with MND like you know, cope differently… you know, one person [with MND] is very different to the other. They have a very individual experience, even though for us, you know, the same diagnosis.* (Nurse, Pall Care)

Professionals found it difficult to predict how the person would present or what emotions they would be faced with during any given interaction.

> *Initially, I just could never predict what you're going to get going in the door, one day you're going in and the entire family are crying, and then you go another and they are just like there [with] the architect sitting in the corner with the plans to do an extension.* (OT, Prim Care)

They also noted that the ways in which patients and families coped with the ongoing changes and challenges they faced directly influenced their own emotional responses and stress levels, which in turn affected their sense of ease or anxiety prior to clinical encounters.

> *I think depending on how the family and the person themselves are coping, will kind of elicit different kind of feelings and emotions in you as practitioner you know, if they are copers and you know they have things in good order and the person seems to be, you know, managing, that's much easier than going into a person who is absolutely devastated, who cries for the majority of the visit… that's the hardest scenario we get, but it's very individual. (Nurse, Pall Care)*

Some participants experienced anticipatory stress on a more personal level, expressing concerns about their own ability to cope with the emotional demands of supporting patients and families.

*It is kind of emotionally difficult and that's maybe one of those things that when the name pops up for admission and you see it's MND, you know... ultimately that's going to be a tough ride*. (PT, Pall Care)

As well as their confidence in managing complex clinical situations that might arise in the future. '*Almost like foreboding stress, if you see referral come in, you're like ohh, hopefully I can deal with this, you know…'* (OT, Res Care)

## Working with uncertainty

The need to continuously anticipate, plan and prepare for future changes, without the certainty of when or if they would occur caused significant stress for participants across all services, *'…and even if a person doesn't need it, often it is a big source of stress of I haven't gotten it yet and do I need to be following up and chasing it?'* (SLT, MDT Clinic).

Participants additionally struggled with their inability to provide certainty about the disease trajectory for patients and their families. They experienced cases when the disease progressed more rapidly than they anticipated '*…the unpredictability of it and that you can kind of have a kind of a situation relatively stable and then all of a sudden it can change, and then it's like literally falling apart a week later*' (OT, Prim Care), and others that stabilised for longer than anticipated, *'it's so unknown, somebody can plateau at certain points like that for a long time'* (MSW, Pall Care). This resulted in participants feeling uncertain about how best to advise, support and prepare patients and families for the future, '*I think it's not really, you know, predetermined, so it can be very hard and they're obviously looking to us as well to try and kind of predict it, even though it's kind of almost impossible sometimes'* (PT, Pall Care).

The challenges of working with this uncertain trajectory were additionally complicated by the certainty of disease progression and '*how it's going to end',* which created dilemmas for participants about the right course of action to take in many circumstances. Participants described difficulty balancing the need to

address and appropriately prepare patients for their future, while recognising that they were still struggling with their present circumstances.

> *You know the most common things that we've seen in clinic in terms of I suppose the patient isn't there yet, in where they think they are on that timeline of progression in their disease, and they feel they're not ready for the walker or they're not ready for the hospital bed in the house. They don't want a wet room in because they... just I suppose, can't face the reality of where they are.* (Doc, MDT Clinic)

Participants commonly encountered *'this mismatch on where they are mentally and where they are physically'* (Doc, MDT Clinic) and faced difficult decisions about whether to address their physical or psychological presentation.

> *...you're trying to get the happy balance and that can be difficult sometimes because like (OT) said, you don't want to miss the boat. But if they're not ready to accept it, yeah, you know you are gonna miss it... I had someone recently, they were like, no there will be a cure next year, there will be a cure, so then how do you broach it, it's really, difficult.* (OT, Pall Care)

To anticipate and aptly support changes in the persons clinical presentation participants were often faced with confronting patients about future changes, they may not have been psychologically ready or able to address. Conversely failing to have these difficult conversations often meant that participants knew they would not be able to provide what the person would benefit from within the required timeframe. They often expressed feelings of having no good option as by choosing to address one need, they compromised the other. The term '*balancing act'* was frequently used to describe how professionals navigated these difficult situations of '*preparing someone for a lot of changes in their life before they're even happening'* (PT, MDT Clinic).

> *...you don't want to go so early [about PEG conversations], that you're scared them, you know, so it's kind of trying to balance it, but at the same time, we don't want to miss the boat that they're stuck on a waiting list for three months and*

*then by the time they get a bed, they've progressed to such a point that they may not be eligible anymore*. (Doc, MDT Clinic)

This feeling of continuously working against the clock, where '*...time isn't quite on your side'* also brought on feelings of anticipatory stress, as participants feared not being able to provide what the person needed within the necessary timeframe. Feelings of uncertainty about the disease trajectory and issues with timely and equitable access to resources compounded this dilemma, as participants struggled to initiate confronting conversations about the future or propose potentially helpful solutions without knowing that these could be delivered or would be suitable for the person when required.

*...you want the patient to be have that need addressed and maybe encourage them to you know to address the need for a gastrostomy, but then part of you knows, well can we offer them that in the appropriate time, so that's tough to deal with from our side... you know, knowing how to accurately advise patients and what is in their best interests*. (Nurse, Charity)

Professionals found it particularly difficult to witness plwMND and their families struggle without timely access to supports that could have significantly improved their quality of life. This ethical strain was heightened by the knowledge that helpful solutions were available but could not be delivered due issues such as ambiguities and delays in decision-making or bureaucratic processes, *'...it's heart breaking to think god what a missed opportunity'* (OT, Pall Care).

*It's very difficult to see somebody trying to manage at home and they're not able, you know, and they're ending up in bed, you know, most of the day not... having not the proper nutrition, not the proper mobility... they're just, they're just lacking care. It's very hard to see that*. (Nurse, Charity)

## '*It all comes down to communication at the end of the day*' - The role of communication and teamwork in creating and mitigating uncertainty

Poor communication and the absence of a standardised approach to co-ordinating the various teams and services involved, contributed to participants feelings of uncertainty, isolation, stress and anxiety. As a result of poor communication between services some participants felt uninformed about the persons journey up to the point of meeting them and about the decisions and conversations that had previously taken place.

> *...its joining the dots of who has seen them, when, what referrals gone where?, who has assessed them for what chair?, when is that coming?, where's the money?, you know like that, there's no centralised system... and like has that family, you know, sometimes you're guessing... has the family been offered this and they refused it because of the acceptance piece? Or have they not a clue about this?* (OT, Pall Care)

In the absence of effective communication between the different teams, services and professionals involved there could be further uncertainty about roles, responsibilities, and plans for certain aspects of the person's care.

> *The service user at any time in our area could be linked in with 9,10, 11 different healthcare professionals or services and again, there's no coordination piece around that. So, I could go visit a client today and bump into maybe someone coming from the [Assistive Technology and Specialist Seating Service], I don't know they're going; they don't know I'm there and the client ends up co-ordinating us*. (SLT, Prim Care)

This primary care participant further spoke about their feelings of uncertainty, isolation and stress arising from fragmented communication, collaboration and support from the different teams and services involved when it came to supporting care, particularly at end-of-life, for plwMND in the community.

> *I don't know where my support is and I don't know where the support is for the client...* and *I feel at that point, I feel huge emotion and stress, anger and*

*frustration and think… here we are now and it's just you and me and I'm trying my best to answer these questions for you, it's not that I don't want to, it's that I hope I'm giving you the right information because I'm not a specialist in MND, you know*.

A willingness and openness to communicate, collaborate and work within a wide multidisciplinary team was identified as an important attribute for professionals working with MND, '*it's not a role somebody can take on solo for sure'* (Nurse, MDTClinic) and '*there needs to be an umbrella approach or a coordinated approach'* (OT, Prim Care). However, a number of barriers were identified to achieving this in everyday practice, such as, '*lack of understanding' or 'lack of knowledge'* about the role and remit of external services and '*sometimes [communication can] be challenging just because of logistics and location'*.

*In my particular area… my team is split and sometimes trying to co-ordinate the kind of multidisciplinary approach can be challenging, and like some of my nurses are not located in my area at all, they're in a different village and my physiotherapist is in a different health centre and trying to co-ordinate that can be a little bit difficult, especially when I really do feel it, this is better managed, through an interdisciplinary or multidisciplinary approach*. (SLT, Prim Care)

Good communication with colleagues both internally and externally effectively alleviated some of the concerns, dilemmas and uncertainties participants faced. While those who worked in the same location as their MDT colleagues, such as in multidisciplinary clinics and palliative care services, often had better experiences of a cohesive multidisciplinary approach for planning and shared decision making, collaboration with external colleagues and services could still present challenges. When there was good communication both within and between teams, participants felt better informed and supported, *'Communication would be quite good between us and the community SLT, so you get a good update before and after about how they got on and you know and what the decisions were'* (SLT, MDT Clinic).

*I think when... you know that there's a patient coming in who's going to have complex needs, it's kind of always good to get ahead of, you know what we can expect, as a team to support each other, just to be able to kind of share the stress and the burden because we know it's going to be tough... so if you can kind of support each other early on with communication, I personally find that... really helpful when we're all on the same page and kind of pre-empting what the issues are going to be.* (MSW, Pall Care)

## Person-centred approaches to managing uncertainty and dilemmas in practice

In addition to good communication, participants identified the need to be prepared for multiple potential eventualities when working with plwMND, but also to be flexible and open-minded in responding to unanticipated changes, patients' psychological needs and choices or preferences for their care. The idea of not having a '*set agenda'* or relying on predefined solutions or rigid protocols was discussed and participants identified how they often needed to quickly adapt and respond to the unique needs of the individual and their situation.

> *I've had to be a little more open minded and flexible during certain interactions with people with MND... having an idea of where I want the session to go but knowing it could go in a completely different direction and just being open to that where it's possible... just giving the person time and going with whatever direction they need to on that day...being more flexible and open helps.* (PT, Res Care)

Participants emphasised the importance of pro-active problem-solving and creative thinking, noting that they were frequently required to come up with practical solutions to unique, evolving, or unforeseen difficulties*, '...not being fixed that there's only one solution... you kind of have to be a bit more creative with coming up with solutions'* (OT, MDT Clinic).

Participants identified how this flexibility also extended to their own clinical ideals, recognising that their professional goals for care did not always align with the priorities, concerns, or preferences of patients and families.

> *… sometimes I find it hard sometimes to accept. You know, you feel they should be going a certain direction and you know, say for example, there's an upcoming appointment with [the ATSS service] and you know, down the road, this is going to make a huge difference to their journey if this gets in place and they decide, oh no, I just don't, I just don't want to go to that appointment next week, up the country or wherever it is and you know, sometimes it's hard to hold back and it's just trying to get it right for them*. (Nurse, MDT Clinic)

And accepting that at times, they did not have all the answers or solutions for the problems patients and families presented with.

> *So, kind of again, reaffirming to yourself each 's time that that is, is part of it, you know, rather than thinking you have to have an answer every time, which is tough*. (Nurse, Charity)

This was portrayed as a challenge that conflicted with their professional values, to fix, cure, help and alleviate suffering. However, particularly among those in specialist MND roles, participants described their responsibility as providing the best available information and framing options in ways that supported patient autonomy and preserved control in decision-making.

> *It has to come from them and it's just, I suppose, being able to frame the information for them in such a way that they have the control over the different choices they can make around their care*. (Nurse, Charity)

Delivering truly holistic, person-centred care was understood to require not only an openness to understanding patient values and perspectives, but also a willingness to support decisions that diverged from the perceived optimal clinical solution and at times involved supporting patients with choices that were perceived as unwise, '*…it's*

*not looking at someone like ohh no, I'm telling you, this is how you should do it, but this is what the person wants. This is what they're going to accept or not accept and negotiating around that'* (SLT, MDT Clinic). However, while adopting a person-centred approach helped professionals to rationalise that decisions were grounded in patients' values and choices, this did not fully eliminate ethical dilemmas, as clinicians continued to balance respect for patient autonomy with their professional responsibility to minimise harm and consider the wider implications of decisions for families and other services involved in the person's care.

### 4.3.2.3 Theme 3: Helplessness – "*I Can't Fix This*"

#### Feelings of being unable to control, fix or change the situation

*'...sometimes, as nurses, you feel you want to fix everything, but sometimes you can't'*.
(Nurse, Charity Organisation)

Across all services, professionals described scenarios when they felt unable to '*fix*', change or improve a situation for a patient or their family. This was felt when the intensity of care required by the patient, outweighed what the health service could provide, '*Lack of home support for families and patients in the community is a huge problem in Ireland... the patient and the family will come to us for support and there's limited resources that we can provide really'* (Nurse, Charity). Participants also experienced how the organisational structures and processes they worked within were often misaligned with the unique and evolving needs of plwMND and further constrained them from delivering truly holistic and person-centred care. Participants described numerous instances where they felt unable to control wider systemic barriers and limitations that adversely affected the quality and timeliness of the care they could provide.

*'…being part of the inpatient service… is something that has really affected me because we're not always able to meet their needs on the ward and we're not able to give them the short admission that they should be able to get, and we're not able to get beds as quicky as they should get it… so the kind of bigger system really fails them in that way… it's so hard to control as one individual or as a team but…it's really not good enough for these patients… it's just so soul destroying*'. (Dietitian, MDT Clinic)

Participants also commonly reported frustration and a sense of helplessness when they were unable to ensure continuity or follow through with care plans due to reliance on external services or agencies, *'Sometimes you feel you have a window and like that you could be doing your piece of work, but you're relying on… other services as well, you know there's some things are out of your control a little bit'* (SLT, Prim Care).

These emotions were further intensified by the limitations of available treatments, particularly the inability to alter the disease's progression or inevitable terminal outcome. Participants frequently described profound feelings of powerlessness and helplessness, and for some, a sense of professional futility or ineffectiveness.

*…and with MND for the reasons we've talked about there's a higher frequency of scenarios where you feel less skilled or less useful to the person, and that elicits stress and then that's where we could kick into… feeling out of control or not having control or feeling powerless and then that's stressful to feel like that. (Psych, Pall Care)*

## The intangible but important job of *'being there'*

Many participants recognised how their presence alone made a meaningful difference. They acknowledged the profound value of simply '*being there'* and '*being a listening ear'*, understanding that emotional support and active listening could provide comfort and help to navigate difficulties, even in the absence of tangible solutions, '*…sometimes you can't resolve issues fully and you're just there to listen'*

(OT, MDT Clinic). However, some participants found this difficult to rationalise, especially when they felt they weren't delivering the kind of concrete interventions or measurable outcomes, typically expected in their roles.

> *I felt well I didn't add anything to the visit with regards to they have all the equipment they feel they need. You know, they're home care package is maxed out, I didn't physically feel I was doing anything, but yet I did feel that the carer got good out of it because she was able to talk... but there's a frustration from I suppose from my part as well, thinking, oh God look, did I do anything there? Like was I able to make any difference but I suppose yeah. You kind of feel you do, but can you measure it? No, you know* (Nurse, Charity).

There was an acknowledged need to *'change focus'* when working with this cohort and professionals reflected on how being present and actively listening to the patient and their family became an important part of the care they delivered, '*It might not be about making change but about quality of life... and yeah, just providing a space for people to reflect or feel that what they're going through is validated'* (Psych, MDT Clinic). In most services participants talked about holding and being in this '*space*' with the person. They described it as time when they didn't try to intervene or offer solutions, they just allowed the person to be frustrated, upset or angry with their situation, and they '*sat with'* the emotion and simply validated their feelings, *'..but sometimes you just have to sit with that because it's just like this is totally normal and I'm not going to pathologise this because, I would feel the exact same way if I was going through that'* (Psych, MDT Clinic). While of benefit to the person living with MND and their family participants noted how the emotional intensity of these moments could be particularly demanding for the professionals involved, especially when they felt unable to change the outcome or relieve non-physical suffering. '*...really it's very hard at times to just be in that space with someone where they're just really distressed or really sad' (*Psych, MDT Clinic).

> *..sitting with somebody who is visibly crying, really distressed, unable to really verbalise how they really feel, or those people that maybe like umm, I was with last week, who like verbalised I just want to die...and you see this more*

*frequently in the patient with MND where their distress is so great and there is really quite little you can do for that, like you can be there, you can support them for that hour that you're in the house, maybe might decide oh god I better go back in three days even though I know I'm just going back to kind of try and sit with it again because ultimately I can't really change this*. (Nurse, Pall Care)

Some felt better able to create or be in this space with the person and described how over time they developed personal resources, boundaries and strategies that allowed them to provide comfort and empathy, without becoming emotionally impacted themselves. One physiotherapist described this as becoming '*comfortable with the uncomfortable'*.

*I definitely think now I would very rarely become upset or emotional or anything like that after an appointment, if ever. For some reason I just feel more comfortable with managing those situations... you almost have like scripts in your head of how you manage it, what you do with yourself during and how you give them space, so I think yeah, that's an experience piece*. (OT, ATSS, 5 years of experience working with MND)

Whereas others, especially those with fewer years of experience, described personal discomfort, sitting with the distress and emotion they were exposed to, especially when they didn't have an immediate solution to offer.

*I think one of the other barriers then for me personally because you can't fix it is that that helplessness on my end. It's like not being comfortable to sit with it, I don't know what, I'm at the end of the line here. What, can I bring in here? And then I tend to, I think maybe it's a self-protective thing, to protect yourself but I tended to not go in as much*. (OT, Pall Care, 1 year experience working with MND)

The need to provide emotional and psychological support for these patients, was described across professions, '*what I find the most stressful is definitely the psychological distress of the patient',* (Nurse, Pall Care). Feelings of being unable to effectively alleviate the emotional pain, existential distress and sadness they

witnessed, intensified the feelings of helplessness and powerlessness participants portrayed, '*you just feel so helpless at times that somebody's going through that, and you can't do anything for the*m, *so it's just, yeah, witnessing somebody suffering is very tough'* (MSW, Pall Care).

Drawing on what was described as '*emotional intelligence'*, to manage these difficult interactions, participants described an attuned and intuitive process of gauging a person's emotional and psychological state and adapting their presence and communication accordingly.

> *It's almost like trying to understand… it's trying to understand where they are at in the trajectory of their journey and trying to be in that space with them. I think that's an important tool to have, It's not easy, but…* (Nurse)

This was further illustrated by participants during the Primary Care focus group discussion:

> *I think being able to read people as in being able to in terms of I think with MND… people fall into very kind of different groups in terms of some people like lots of information and like to know everything and what's going to happen… and other people like just want to be in the moment and deal with the crisis as it comes along… I think it's kind of being able to kind of see that in people because it's not something they're going to share or volunteer or be aware of themselves. (SLT)*

> *…And as you say [SLT] it's knowing when to shut up and it's knowing when to talk and it's knowing when to just, you know, when it, when it's time to leave, you know when you just need to sit there and stay sitting there, it's when you, when you know to step out as well but also to know that time when you just need to stay there two minutes longer. I think that comes with experience (OT)*

Several participants reflected on their early experiences working with plwMND, as well as those of new colleagues or team members in their respective services. They described how initial feelings of uncertainty and their perceived inability to

effectively help patients often led to a strong impulse to disengage or avoid direct involvement in their care. *'I didn't know how to approach this'* and *'avoidance… especially in in those early days and my very first case, that was very strong'*. Over time, however, many participants noted that their ability to engage with these complex interactions and their confidence in providing meaningful support grew primarily through clinical experience and exposure. As such they highlighted the need for greater support and guidance for professionals, especially newer team members, who may struggle with the emotional complexities and sense of helplessness often experienced when providing MND care. *'I think to be mindful of that as well for new graduates and new staff members as well… you know like an acknowledgement that support is required'* (OT, Prim Care).

> *'If I go back 20 years ago, I think I would have struggled in terms of, I'm definitely walking by that one now because I'm so anxious in terms of I don't know what I'm going to do… sometimes I find now even… I had somebody very recently who was very distressed, and I was almost like, you know on the verge myself and I just named it out and I said, you know what you are absolutely right… I completely concur with you, and you know then… I suppose, I to try and have those reassuring pieces in terms of… we will always do our best to support you… I do find it really hard, but you know, I suppose we've had quite a lot of patients with MND over the years that you just get a bit more easy with this and… you just get a little bit more easy with them'* (Nurse, Pall Care).

## Positive reframing – finding purpose and meaning

Participants, particularly those working in MND specialist and palliative care roles, discussed the importance of being able to reframe hope and foster a sense of positivity when supporting patients and families, especially in response to the feelings of distress and hopelessness that were often expressed. They emphasised the value of focusing on what the person could still do, while sensitively identifying and highlighting sources of positivity. This approach could help patients and families

find new sources of meaning and purpose amidst the challenges of the broader situation.

> *What certainly is challenging is, you know, with MND there is rarely an improvement, you know you have to try and help them see the, I suppose what is positive about where they are now and it's trying to find that, and sometimes if you go into a family situation where they're just having a bad day, they're all overwhelmed and feeling down and you could be there half an hour or you could be there an hour and a half, you know, just chatting, just sitting with it and hopefully I always think, jeepers, if I can just lift it a little bit*. (Nurse, Charity)

These participants highlighted how this shift in focus not only benefited the patient and their family, but also helped mitigate their own feelings of helplessness. It helped to reinforce the value of every compassionate interaction, small change, or piece of advice, demonstrating how even the smallest actions could make a meaningful impact on the person's life, no matter how minor it might seem in the larger context.

> *...but we're kind of in this position where when everything is almost stacked against them, you can offer something, you can offer like a simple thing, of like a walking aid or foot splint that maybe allows them to have a small little bit of independence in a completely deteriorating situation, because I think if you thought of the latter and where the disease goes, you could get very upset and very emotional, but I think that's what I almost kind of have to hold on to a little bit and that is that it is an opportunity to provide something to people and or guide them in the direction of, you know what they can do or access*. (PT, MDT Clinic)

Participants who embraced this perspective, focusing on being present, on what they could do and the value of small interventions that enhanced the patient and family experience, found their work to be deeply rewarding and fulfilling. They spoke of deriving meaning and purpose from the positive impact, no matter how small, that they were able to have on the patient's life, "*So I think it's definitely the impact that you can make on their lives. I suppose one of the things that I'm beginning to*

*understand is that the positives… they are minute little things… really small gains that actually feel really enormous, for people with MND"* (MSW, Pall Care).

> *…and just like you know that little things like that make you feel like I'm doing something for them that is beneficial, even though it is not going to make a huge difference in their life. It is little things, but that it's also making a huge impact. So, I say like you know, like when I'm saying little things, that is making a little difference, is the things that I find rewarding when we look after patients with MND.* (Nurse, Pall Care)

### 4.3.2.4 Theme 4: Managing the Emotional Impact of Working with MND

#### '*It takes a personal toll'*

Participants across all services acknowledged a personal toll and the emotional impact from working with the loss, grief and sadness that can surround plwMND and their families **'**… *it's very emotionally draining, very difficult, like very sad'* (SLT, MDT Clinic). Many participants shared experiences of themselves or colleagues becoming emotional or tearful because of patient circumstances and often described how it could be challenging to separate this from their personal lives. *There are evenings where you come home and you, you're drained both physically and mentally* (OT, MDT Clinic).

> *We've all had colleagues come out of appointments with people with MND upset and in tears and maybe needing to say to them, you know, go have coffee or, you know, just go home, like, just finish and go home now.* (OT, ATSS)

This was also discussed during one of the specialist palliative care focus groups, and is illustrated by the following:

*…when the people start crying over the stuff that they wanted to do, and it is very much like that, you know, you're feeling helpless and you are emotional for them as well, so it's very difficult at that time*. (Nurse)

*They can stick with you though those cries, they are like shrieks. Maybe that's the only noise that person can make you know, I often think about that when I go home, it's very hard to leave that at the door*. (OT)

The longer-term psychological impact of this work was also recognised and the implications for staff retention, recruitment and professionals' own well-being:

*…there's no doubt about it. I think, generally with MND there's a vicarious trauma, you're always going to have sadness… and it does bring that burden in your heart that it's just, it's difficult to manage*. (Nurse, Charity)

*I think it leads to just emotional burnout is what I felt on the ward at that time, and people being really upset actually like, you know, tearful at times that how strenuous and demanding the care for that person [with MND] was and I think it has led* to *even staff turnover, people leaving and people being off sick… I think it was a massive issue and I think it continues to be*. (OT, Res Care)

One Occupational Therapist disclosed availing of professional support due to the impact of this work on their psychological well-being, '*… I feel like comfortable saying it, but I went to counselling over working with people with MND and really struggled emotionally big time'*. The perceived psychological toll and personal impact was also one of the main reasons why many participants felt other professionals avoided working in MND specialist roles.

*…they don't necessarily want to get into the weeds of that emotion. You know, so they want to kind of protect themselves. So, like very few people have wanted to come to [work in] the clinic… since I've been doing it*. (PT, MDT Clinic)

*People definitely say, they definitely couldn't do it. They'd be too upset. You know, they'd be going home and thinking about the person, that you know, think about the patients all the time*. (SLT, MDT Clinic)

## Helpful and protective factors for professionals working with MND

Several factors were identified that helped to reduce or manage the personal toll of working with plwMND. Some felt that having only a small proportion of plwMND on their caseload was psychologically protective, and perceived that working solely with this cohort would be significantly more challenging, '*I think it would be very difficult in say in an MND unit or something that, would, I think that would be very, very difficult, that would, the danger of burnout would be very, very, very high'* (Chaplain, Res Care). This was echoed by a professional working full time with MND, who also questioned the sustainability of the career, *'I wonder to myself, is this very long term, I will keep going for another while, but I'm not sure if it's if it's a long-term professional choice because it is very, very sad work yeah, for me personally'* (Nurse, MDT Clinic). Despite the challenges, others working in specialist MND roles described a sense of fulfilment that helped sustain their commitment to the field.

> *I mean, there's no doubt that it is challenging, but for me I enjoy it, so I do see myself staying within the MND sphere, I just really enjoy the team, I really enjoy working with the patients... for me I've been in this a long time now I feel like it's probably Stockholm syndrome, but no, I really do enjoy it though*. (Doc, MDT Clinic)

The ability to pace or distribute the workload was also perceived as helpful. Those working in the community setting spoke about limiting the number of patient visits in a day and alternating difficult visits '*with some nice visits'*, for patients whose condition was more stable or had a less complex presentation. In inpatient settings, nurses in particular spoke about the need to distribute the workload across wards '*I think it's only one [person with] MND per ward is more than enough, rather than two, two patients too much'* (Nurse, Res Care) and among the professional team.

> *...as a nursing team we would be aware of that and saying look, you know you're not going to be looking after that patient every day. We need to share that person*

*around because, take turns because, it's so it's so tough, you know.* (Nurse, Pall Care)

Other members of the multidisciplinary team felt that having a varied caseload and shorter periods of exposure was protective for them and recognised the intensive and often time-consuming care provided by nursing and care assistant colleagues.

*I think I would find it more challenging if I was working perhaps in nursing or care where I would be maybe seeing a challenging patient for a long period every day. I could see how that could lead to more burnout, whereas my caseload is more varied.* (PT, Res Care)

Team and collegial support were strongly valued and identified as important protective factors by participants across all services. *'There are so many cases I don't know how I manage, sometimes emotionally, you know, without having the opportunity to talk to a colleague about it'.* (SLT, Prim Care)

*I think it's the team that make us ok like that... like there's always someone to listen... there's always someone to chat to, debrief to... and you're not taking on patients' issues in isolation, you're taking them on as a team.* (OT, MDT Clinic)

Participants experienced a general lack of understanding or hesitance to talk about their work from their family, friends, and wider social circles, '*...because I think like when I speak to anyone else and say you're working with... [MND] and everyone else is like, how do you work with those patients?'* (OT, MDT Clinic). This resulted in some participants finding it difficult to seek emotional support from their usual sources and is potentially one of the reasons why team and collegial support was so strongly valued and important to them.

*...I talk to my mom, like would be very close. I can't talk to her about work because she just tells me I don't want to hear that, I don't, your jobs too sad and I don't want to hear about it.* (SLT, ATSS)

While those working in settings with immediate access to team members and colleagues often had greater access to this form of emotional support.

*I think that's what's really good is having the team around and being able to discuss at team meetings and just getting other team members experience as well and thinking right... you know, I'm not, I'm not experiencing this, I'm not experiencing this on my own.* (Chaplain, Res Care)

Those working in the community or patients' homes could find it difficult to access the same level of collegial or peer support.

*I suppose the challenge is that we are lone workers, and we are going out by ourselves every day... we could be having very big conversations with people about very big things, like at the end of the day death is the biggest conversation you're ever gonna have, and maybe sometimes not having that... just when you're working in the hospital environment, you can maybe pop out of the room and have a chat with somebody...or there's somebody else that's just had that conversation with the same person*. (Nurse, Charity)

Participants described the powerful sense of shared understanding that developed within teams who witnessed and experienced the same emotionally charged situations and challenging clinical scenarios. However, they also noted that most services lacked dedicated time or formal systems for peer support and debriefing. '*we really don't have a formal system of support'* (SLT, ATSS), '*I explained that sort of sadness and grief that I feel when somebody's diagnosed, but we don't really get an opportunity to get some help around that... we don't get any support'* (Dietitian, Primary Care). Many felt that allocated time and recognition of the need for team debriefing, and communication was needed, '*I mean like not only for the patients needing to debrief after the clinic, you know we might need to ourselves as well, but we like, we're up against time*' (Nurse, MDT Clinic).

*I often think if we had that more even not formalised, but you feel like sometimes I feel like, oh my god, if I'm debriefing, I'm not actually working, you know, that you have that time... and even for it to be acknowledged, I suppose, the effect is has on us emotionally as well*. (SLT, Prim Care)

For most, reflection and debriefing were not currently integrated into their practice. Some felt that it wasn't prioritised within their organisation and that there

was an expectation that they should be accustomed to managing the emotional demands of the work *'…often it is just because it's like 70% probably of what… (the team) and I see are probably MND… you know, there is just this kind of idea that I'm sure you're used to it'* (SLT, ATSS). Whereas protected time for team reflection and de-briefing was highly valued by those working in specialist palliative care, who had access to this forum of emotional support, *'…I know from experience with patients on a palliative care unit, you know, kind of having de-briefings and team kind of de-briefings about looking after patients like that is brilliant*' (MSW, Pall Care). Supervision and support from senior colleagues and line managers was also perceived as helpful, *'That's really important I think to have support from your line manager as well in terms of being able to recognise when something is too difficult and too stressful, that if you need more support'* (OT, Res Care).

Participants discussed various ways of acknowledging the emotional weight of their work and creating a protective distance between their professional and personal lives. An Occupational Therapist working in an inpatient palliative care unit spoke about visiting patients with MND earlier in the day in an effort to create physical distance between challenging work situations and their personal life, *'I started going into those kind of real challenging people early in the day, so that later on in the day I was nearly able to try to leave it here'*. The ability to be self-aware of their own feelings, create distance, implement individual coping mechanisms, and use distraction techniques were additionally identified as tools that helped to maintain their own-psychological well-being and consequently their ability to give their best to patients when they were at work.

> *So being very mindful… what do I need to take care of myself and how do I need to prepare myself… I'm not just going to override my stress, you know, I'm going to acknowledge, ok, this is difficult…* (Nurse, Pall Care)

> *I suppose the one good aspect is we are on the road, so you would have at least probably a 40 minute drive home, to get home, and I personally, I use that time, I phone a friend or a colleague or you know just to I suppose unwind before you get home and just you know, let it go.* (Nurse, Charity)

*You have to have your own coping mechanisms for managing the transference of what you're seeing in front of you, or you just wouldn't be able to do your job.* (Psychologist, MDT Clinic)

*When I finish work, I just finish it. Leave it there. Tomorrow is another day. Do something nice. Go for a walk. Chill out. I practice yoga. I think that has kept me, you know, sane the last year.* (Nurse, MDT Clinic)

Finally, participants particularly those working in MND specific services also spoke about the use of appropriate humour, '*umm, it's not uncommon for us to, like, have a laugh and a joke, you know?*' (Psychologist, MDT Clinic). This was considered '*psychologically protective*' and a '*coping mechanism'*, for managing '*the gravity of it all, respectfully, you know, sometimes [humour] can help'* (PT, MDT Clinic).

## What sustains professionals in these roles?

A number of factors were identified that sustained and motivated professionals, particularly those working in MND specific services, to continue working in this clinical area. Across all services, participants expressed very strong feelings of '*awe*', '*inspiration*' and '*admiration*' for patients and their family's ability to adapt and cope with the adversity they faced, as one Occupational Therapist described '*it's the resilience that those patients have that allows you to keep going as well'* (OT, MDT Clinic). These participants experienced how the '*strength of character'*, '*determination*' and '*resilience*' of the MND patients they worked with, gave them enhanced perspective and appreciation for both their own health and personal lives. '*Sometimes I'm overwhelmed by how people get on with it and are, just the resilience of families and how they just embrace it'* (Nurse, Charity).

*I've been actually really surprised by the amount of hope that actually families and patients hold, and I think it really, what I've seen psychologically, it displays the best of people, like that resilience and that hope. Sometimes I'm just flabbergasted... and I just think that's like exceptional, like the flexibility of your psyche to be able to do that is just extraordinary... it makes me a lot more*

*grateful for what I have in my life… I am just much more aware of like what I have, and like, how grateful I should be for what my body can actually do.* (Psych, MDT Clinic)

The gratitude and appreciation participants received, '*You know when they come in and they're kind of glass half full or they kind of, yeah, acknowledge the benefit they are getting from the clinic, that can be very rewarding'* (Dietitian, MDT Clinic), as well as the perception of having a meaningful job and knowing that they helped and supported people during an extremely difficult time was perceived as very rewarding, '*…it is uplifting, you know, when it's important… there's a certain satisfaction to trying to help people in their hour of need'* (PT, MDT Clinic).

*So that kind of aspect of, oh well, maybe that person's life tomorrow is going to be just a little smidge easier because they spent half an hour chatting it through with me, that is kind of one of the rewarding things.* (SLT, MDT Clinic)

Finally, participants across each service felt that working with MND offered them a huge learning experience *'It's the best learning curve ever, absolutely, best learning curve ever'* (OT, Prim Care). They felt that the challenges they faced inspired them to learn more about the condition **'…***you're always motivated to get better at understanding all the different facets of it and work with your team, so that collectively you feel there's always good to do better and better'* (Psych , Pall Care) and to enhance their own clinical knowledge and skills, '*…one of the things that I found with those more difficult cases, it inspires you to go learn more, you know like… even that brilliant… [MND] study day, that was brilliant'* (OT, Pall Care). Participants described experiencing both personal and professional growth from their work with MND patients and from working with colleagues in challenging circumstances.

*You're constantly learning from them as well, because their experts themselves, I mean, as I was saying like they come up with ways of doing things and sometimes you can learn from one person and apply it to the next person who comes in, that you're also like learning from them.* (OT, MDT Clinic)

*…I actually think it's really nice that we get to work together because there's such a huge variety in terms of how different people handles it, and you get to*

*learn a little bit of how that person holds themself and the language they use, and you kind of take from all of those bits to kind of make your own version of what you're comfortable with.* (SLT, ATSS)

Participants reflected on how the experience of working with MND helped them to become better communicators, '*I think for me personally, well, how I've benefited is I think I've definitely become a better communicator; I think I've been able to kind of reflect and kind of manage those challenging communications and interactions a lot better'* (OT, Res Care) and overall more understanding and empathetic clinicians.

*I think just that overriding aspect of what exactly does patient centred care mean because it is a client group where you have to really embrace that, and then even then, I would find, I would have taken that into other patients. I would be working with a patient where maybe we can't fix things or they're not on a rehab trajectory and just like (OT) was saying, just really kind of listening to what that person wants.* (SLT, MDT Clinic)

The continuous learning and variety in the clinical work from the different individuals, clinical presentations, and dynamics they encountered was recognised as a sustaining factor, particularly for participants who expressed an interest in continuing to work in this clinical area.

*I think it is a job you could stay in for life because you're still always surprised by the different questions you get, the families that you meet, like, there's still always something, jeeze I've never seen or heard of that before, and this is a new challenge... I've been in the job like four years... but I know I still have so much more to learn as well.* (Nurse, Charity)

## Additional Analysis

Additional supporting quotations for each of the themes and sub-themes presented above are provided in Appendix J. In addition, individual needs and resources available to each of the respective services were identified as part of this analysis and are presented in Appendix K.

Finally, examples of situations identified by participants in this study as potentially contributing to experiences of moral distress when working with patients and families living with MND were extracted from this dataset. These situations were developed into 24 statements and formed an important part of the online survey that was developed and distributed in Phase Three of this research. Further information about the development and application of these statements to identify potential causes of moral distress in this population is presented in Chapter 5 of this thesis (5.2.3 Question Development and Measurement Tools).

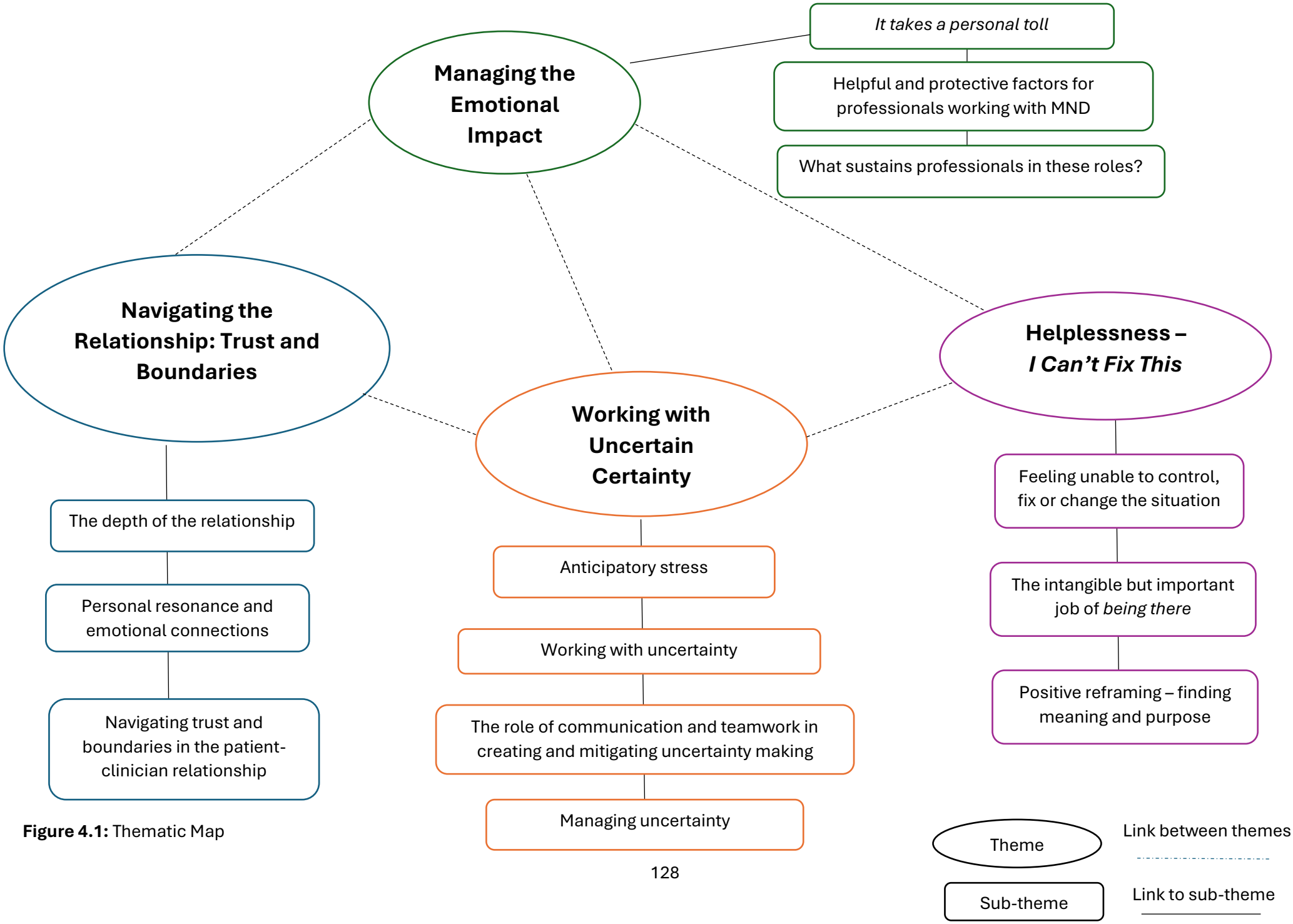



**Figure 4.1:** Thematic Map

## 4.4 Discussion

This study is the first in Ireland to explore the experiences of HCPs across the full spectrum of community based and specialist care services involved in the care of plwMND. It offers novel insights into the emotional and practical complexities that professionals encounter when supporting people living with this progressive, multifaceted, and incurable condition. The findings highlight both the challenges and the deeply rewarding aspects of delivering MND patient care. These insights offer a deeper understanding of the professional experiences involved in working with individuals and families living with MND, capturing nuances that have been typically underexplored in the existing literature.

In the following sections, the themes generated from the analysis of focus group data are critically considered in relation to the broader MND literature and relevant frameworks from palliative, neurological, and psychosocial care. Following on from this the discussion explores potential strategies to enhance professional support, promote staff well-being, and optimise professionals' capacity to deliver sustainable, high-quality care for MND patients and families. Implications for clinical practice, workforce development, and future research directions are also discussed.

### 4.4.1 Navigating Therapeutic Relationships, Trust and Boundaries

Theme one highlights the complexity of the patient-clinician relationship in MND care, where professionals are required to balance the dual, and at times conflicting, roles of empathetic caregiver and objective practitioner (Funk, Peters and Roger, 2017). Theme 1 revealed that clinicians frequently develop close, trusting relationships with patients and families as they provide ongoing support across a trajectory marked by increasing dependency, emotional vulnerability, and anticipatory grief. Such relationships are deeply valued by patients, families (Pinto *et al.*, 2021), and professionals alike (Hansen, Burton-MacLeod and Schellenberg, 2024; Rawlinson *et al.*, 2024; Monteiro, Ali and Laranjeira, 2025) and they are widely recognised as central to the delivery of compassionate, person-centred care (Lerum, Solbraekke and Frich, 2017). However, a novel contribution of this study is the finding

that these therapeutic relationships can also challenge conventional professional boundaries. Similar difficulties in negotiating boundaries have been observed in other clinical settings where clinicians engage in prolonged and emotionally intensive relationships with patients and families (Cousins, Bradshaw and Bonner, 2020; Webber, 2020). However, in the context of MND, several distinctive features, including its incurable and debilitating nature, the sustained intensity of professional involvement, systemic barriers to providing adequate levels of care, the personal resonance it can evoke, and the highly emotive nature of many patient and family circumstances, appear to amplify the sense of commitment and emotional entanglement for HCPs working with these patients and families.

Participants in this study described establishing both practical and emotional boundaries in their work. Practical boundaries defined the limits of support that could be provided within the constraints of time, resources, and professional roles. Yet upholding these boundaries was often described as morally challenging, as available care frequently fell short of what professionals believed was necessary to meet identified patient and family needs. As a result, clinicians were at times placed in difficult situations where they felt pressure to stretch, or even overstep, their professional boundaries. This tension was heightened by the relationships they had formed, the intensity of unmet needs, the emotional strain of witnessing patient distress and caregiver burden, and the added pressure to sustain patient and family trust to ensure continuity of care as MND progressed.

As Lisiecka *et al.* (2025) emphasise, trust is foundational in the care of plwMND. This study supports these findings but as outlined in Theme 1, these participants identified how trust within the patient–clinician relationship is not static and as the disease progresses, can be challenged by systemic barriers as well as condition-specific and interpersonal factors. Communication impairments, difficulties with psychological adjustment, and the active involvement of informal caregivers as co-providers of care all influence engagement and, in turn, the establishment or maintenance of trust in the therapeutic relationship. Among these, cognitive and behavioural changes also posed some of the greatest challenges for professionals in this study. While these changes are well documented for their impact on

relationships with family caregivers (Lillo, Mioshi and Hodges, 2012; Watermeyer *et al.*, 2015), their influence on professional-patient relationships has received much less attention, especially in settings where clinicians function as primary caregivers (Ushikubo *et al.*, 2021). For professionals, such changes can erode reciprocity and trust leaving clinicians feeling personally challenged, vulnerable, or even undermined in their role. Early identification and collaborative management of cognitive and behavioural changes is important to help sustain relational trust, professional integrity and team cohesion (Francis *et al.*, 2023). Further research should consider in greater depth how trust evolves over time in MND care and how clinicians can be best supported to navigate boundaries and relational complexities to deliver consistent and compassionate care in the face of physical and oftencognitive, and behavioural decline.

Clinicians in this study also outlined situations of blurred personal–professional boundaries, where personal empathy for patients and families intersected with their professional responsibilities. These moments often reflected difficulties in maintaining emotional boundaries, as clinicians balanced authentic compassion and connection with the need to protect their own emotional well-being and professional objectivity. This was portrayed as a persistent tension between '*being close'* and '*maintaining distance'*. In this study, establishing emotional boundaries was portrayed as an individual and adaptive process shaped by multiple factors, including the emotional intensity of the situation, identification with the patient or family, prior clinical experience and levels of unmet need identified. Similar adaptive approaches have been observed in areas of practice involving care for critically ill or dying patients (Erikson and Davies, 2017; Finotto *et al.*, 2022), underscoring that professional boundaries are often more complex and nuanced than formal codes of practice suggest and frequently require more flexible interpretation based on the unique needs of each situation (Doel *et al.*, 2010). While boundaries in extreme situations (e.g., sexual relationships with patients) remain unequivocal and morally prohibited, less is understood about how emotional reactions influence clinicians' appraisals, decisions, and personal-professional boundaries in highly emotive contexts (Childers and Arnold, 2019).

In this study, emotional distancing emerged as a strategy that some participants employed to manage the gravity of the situations they encountered when working with this population. This approach likely reflects a broader professional norm of grief suppression and emotional detachment, often reinforced by healthcare cultures that equate stoicism with competence and professionalism (Funk, Peters and Roger, 2017). While this can serve as a protective mechanism to maintain functioning in emotionally charged environments, reliance on detachment can also impact patient satisfaction and engagement in care and introduce challenges for professionals in meeting the emotional needs of dying patients and families (Funk, Peters and Roger, 2017). Research indicates that excessive emotional distance in therapeutic relationships can erode trust, perceived empathy, diminish relational warmth and amplify power imbalances, thereby creating distance in relationships that are dependent on trust and collaboration (Smythe *et al.*, 2018; Darley *et al.*, 2024). The implications can also extend beyond patient and family care to the well-being of professionals themselves. The habitual suppression of professional grief and related emotions has also been linked to decreased job satisfaction, heightened risk of burnout, and overall reduced professional well-being (Lathrop, 2017; Ansari, 2022; Crape *et al.*, 2025; Phillips, Trainum and Thomas Hebdon, 2025).

In recognition of these risks, some scholars have argued for the importance of reframing emotional responses to grief when working people at end-of-life, not as signs of weakness, but as expressions of humanity, meaning and professional growth (Owens and Greenawald, 2023; Feng, Shen and Li, 2024). This perspective suggests that experiencing and acknowledging emotions and grief, under the right conditions, can serve as a protective factor against the cumulative strain of caring for people at end-of-life (Childers and Arnold, 2019). Yet, navigating the tension between professional boundaries and relational engagement is complex (Lampe *et al.*, 2023). It requires flexible, context-sensitive responses that evolve with the needs of patients, families, and clinicians themselves. Achieving this balance requires sustained personal-professional reflection as well as organisational cultures that foster open dialogue about issues such as professional grief, uncertainty, vulnerability, and emotional challenges (Fronek *et al.*, 2009; Sherratt and Hersh,

2010). In the absence of such support structures, professionals may find themselves ill-equipped to manage complex relational dynamics, increasing the risk of inadvertently crossing professional boundaries or, conversely, of feeling that their own personal boundaries have been compromised (Lampe *et al.*, 2023).

The emotional stamina required to sustain therapeutic relationships with critically ill patients has been widely associated with compassion fatigue, burnout, and emotional trauma in other areas of practice (Van Mol *et al.*, 2015). Participants in this study, even those working in palliative care contexts, recognised that the relationships they form with MND patients and families are typically more intensive and enduring than other patient cohorts they work with. Yet, professional quality-of-life indicators such as compassion fatigue and burnout have not been widely examined in the field of MND care to date. Although participants did not explicitly discuss their own mortality salience or death anxiety, many described the confronting nature of MND, often linked to the profound loss of self and independence they witnessed. Several reflected on the difficulty of imagining how they themselves might cope in a similar situation. Without adequate support to process these encounters, such existential distress may contribute to avoidance of close relationships or difficulty sustaining long-term engagement with patients and families, particularly in cases that resemble the professional's own personal life circumstances. These challenges are compounded by the fact that MND does not discriminate by age or life stage and frequently affects individuals in the prime of their lives. As a result, as outlined in Theme 1 professionals often encounter patients whose circumstances closely mirror their own. This echoes the findings of Pessin *et al.* (2015), who found that professionals experienced greater emotional strain on the loss of patients with whom they had built long-term relationships, or when there was something about a patient case that reminded them of themselves or a family member.

While exposure to death and loss is unavoidable in MND care, interventions that directly address confrontation with death and death anxiety may help to mitigate the emotional toll on professionals (Nia *et al.*, 2016). Future research should consider the benefit of strategies such as clinical supervision, peer support, reflective practice

groups, and self-care interventions in enabling professionals to manage and process the deeply personal reflections and emotional responses that arise in these roles.

It is also important to recognise that not all emotional reactions in caring for dying patients are negative or distressing. Morgan and Gazarian (2023) describe how professionals experience positive emotions when they feel they have supported a *"good death"*, characterised by those in which the patient and family accept the dying process, the patient has good symptom control and emotional support. Similarly, Zambrano et al., (2014) found that palliative care specialists often derive meaning and fulfilment from being present with patients and families at the end of life. These findings are echoed in Theme 1 of this study, where professionals emphasised that having the opportunity to develop and sustain therapeutic relationships that enabled the delivery of holistic and person-centred care, were one of the most deeply rewarding aspects of working with this population. Therefore, positive experiences of a trusting therapeutic relationship, have the potential not only to enhance perceptions of quality care, continuity, and the experience of a good death for patients and families, but also, to foster professional fulfilment, job satisfaction, and ultimately staff retention. This underscores the importance of ensuring adequate supports are in place, that help professionals manage the emotional demands of their role, maintain appropriate personal-professional boundaries, and sustain trusting and collaborative therapeutic relationships.

### 4.4.2 Working with Uncertainty

The second theme identified feelings of uncertainty as a consistent and shared experience among professionals, driven by the heterogeneous, unpredictable course of MND and the lack of effective treatment options. Han et al. (2019) describe uncertainty as a pervasive yet often under-recognised element of clinical practice, while more recent work by (Zybarth *et al.* (2024) and Zybarth, Inhestern and Bergelt (2025) has shown that HCPs working with rare, complex, progressive, or poorly understood conditions face heightened levels of uncertainty. This is largely attributed to limited knowledge and guidance on how to approach care for these conditions,

with professionals frequently required to navigate unclear treatment pathways, uncertain prognoses, and unexplained symptoms. Zybarth, Inhestern and Bergelt (2025) were also the first to show a direct association between uncertainty-related anxiety and increased burnout among professionals working with rare diseases. To our knowledge, this current study is the first to explicitly consider the impact of uncertainty on HCPs supporting plwMND. While earlier research has emphasised the emotional and practical burdens of uncertainty for patients and caregivers (Harris *et al.*, 2018; Trucco *et al.*, 2024) our findings extend this by drawing attention to the significant challenges and stressors faced by clinicians themselves. Although the intensity and sources of uncertainty varied according to role, experience, and familiarity with MND, it was consistently recognised across all professional groups as a defining and demanding feature of MND care.

An interesting finding from this study was the identification of anticipatory stressors outlined in Theme 2, with many participants reporting feelings of anxiety, self-doubt, lack of preparedness, and emotional apprehension, both before certain interactions and in relation to potential future challenges or changes in a patient's clinical presentation. These apprehensions were shaped by the certainty that deterioration would occur, coupled with uncertainty about when and how it would unfold, and whether they would be able to effectively meet evolving needs. This reflects a distinct psychological burden that extends beyond immediate clinical demands and was often intensified by previous difficult experiences in caring for plwMND.

Anticipatory stress can be defined as an elevated stress response triggered by the expectation of a difficult or unpredictable situation (Grace, 2024). Although many anticipated scenarios may never materialise, such stressors can significantly impair cognitive functioning, emotional well-being, and decision-making capacity (Starcke *et al.*, 2008; Hyun, Sliwinski and Smyth, 2019; Kramer *et al.*, 2022). As a result, professionals experiencing such apprehension before patient encounters may struggle to remain fully attentive, feel overwhelmed by multiple possible outcomes, and encounter difficulty supporting clear decision-making around care. While most research on anticipatory stress has focused on general psychological or high-performance settings (Van Paridon *et al.*, 2017; Pulopulos, Baeken and De Raedt,

2020), its role in healthcare remains underexplored (Schlatter *et al.*, 2022). Given the unpredictable and evolving trajectory of MND, it is crucial to deepen our understanding of how anticipatory stress develops, how it may affect care delivery and professional well-being and how it can be recognised and managed. Importantly, the period of stress anticipation presents a critical window for intervention (Schlatter *et al.*, 2021) and offers an opportunity to equip professionals with the knowledge, skills, and strategies needed to navigate both avoidable and unavoidable uncertainties inherent in MND care.

As highlighted in Theme 2 participants also identified how feelings of uncertainty affected their ability to communicate openly with patients and families in certain situations and created challenges when supporting decision-making about future care. Many also expressed a persistent tension, that has been described in previous research, between their desire to be fully prepared and the reality that future eventualities were not always possible to either predict or prepare for (McConigley *et al.*, 2014). The uncertainties they experienced commonly related to the trajectory of disease progression, the timing and appropriateness of interventions, patient and family's readiness to engage in difficult conversations, and the availability of services and resources. These sources of uncertainty align closely with the models proposed by Han, Klein and Arora (2011) and Pomare *et al.* (2019), both of which identify scientific (e.g., diagnosis, prognosis, causal explanations, treatment recommendations), practical (e.g., care structures, processes, and systems), and personal (e.g., psychosocial, existential, and ethical) domains as the core areas of uncertainty encountered by HCPs working in complex settings. A key advancement in Pomare *et al's.* (2019) revised model is its emphasis on the dynamic, interrelated, and system-wide nature of these uncertainties, recognising that they rarely occur in isolation and often interact in ways that compound their impact on clinical decision-making and care delivery. This resonates with the findings of this study, where personal and ethical uncertainties, such as deciding when to initiate conversations about specific interventions, balancing emotional cost with the window of opportunity, were often compounded by practical uncertainties about service and

resource availability, as well as scientific uncertainties regarding prognosis and the potential benefits of the intervention.

Previous research further demonstrates that openly communicating uncertainty to patients can be challenging for HCPs, as acknowledging uncertainty is often associated with perceptions of professional failure or concerns about undermining patient trust (Simpkin and Armstrong, 2019). Despite concerns that addressing uncertainty may undermine trust, numerous studies have shown that when communicated transparently and addressed collaboratively, uncertainty can actually strengthen the patient–professional relationship by fostering authenticity, empathy, and mutual understanding (Armstrong, 2018; Bontempo, 2023). For HCPs, however, this remains challenging, as it requires not only confidence in explaining complex and often ambiguous information but also the interpersonal skills to navigate diverse and sometimes conflicting perspectives that can arise when decisions are unclear (Etkind *et al.*, 2023). In MND care, these challenges are particularly evident in complex treatment choices such as gastrostomy, non-invasive ventilation, or advance care planning, where the "*fine line*" between providing information early enough to support autonomy and advance care planning, yet not so early as to overwhelm and impact relationships, is often difficult to identify and effectively manage (Gale, 2015).

Shared decision-making (SDM) offers a valuable framework in this context and was implicitly described in Theme 2, by participants working in specialist MND services in this study. SDM encourages the open acknowledgement of uncertainty while supporting patients to actively evaluate options in line with their values and priorities (Fisher and Ridley, 2012; Giuseppe Parisi and Peter Konstantin Kurotschka, 2022). This approach not only aligns with the principles of person-centred care but also helps to distribute responsibility, reducing decisional conflict and reassuring clinicians that decisions and care plans are firmly grounded in patient priorities and values. Embedding the normalisation of uncertainty as an inherent feature of working with conditions like MND into professional education and training programmes, while simultaneously equipping professionals with the skills to engage confidently in collaborative, values-based discussions and decision-making, may enhance

professional confidence, improve communication, minimise delays in decision-making, and mitigate stress in these emotionally and ethically demanding interactions (Medendorp *et al.*, 2021).

Effective team-working and interprofessional communication that supports anticipatory, parallel, and collaborative care planning were identified in this study as crucial enablers for HCPs navigating the uncertainty, ethical and clinical dilemmas inherent in working with plwMND. This finding aligns with broader literature, which highlights the value of coordinated care in reducing the emotional and cognitive burden associated with working with clinical unpredictability (Ellis-Smith *et al.*, 2021) and reinforces previous research demonstrating the necessity of MDT support in MND services (Hogden *et al.*, 2017; Hansen, Burton-MacLeod and Schellenberg, 2024; Walls *et al.*, 2024). Fostering cohesive and supportive teams that provide psychological safety enables professionals to openly share and address their uncertainties without fear of judgment or criticism (Murray, Kelly and Hanover, 2022; Peddie *et al.*, 2025). Challenges with interservice communication and siloed working, widely reported in earlier studies (Hogden *et al.*, 2012; Ushikubo and Okamoto, 2012; McConigley *et al.*, 2014; Cipolletta and Reggiani, 2021; Olesen *et al.*, 2022), were also found in this research. This fragmentation not only undermines patient and family care and erodes trust in the healthcare system (Pinto *et al.*, 2021), but also contributes to professionals' feelings of uncertainty, isolation and stress, while restricting the provision of essential information, resources, and services.

While openness to communication and collaboration across service boundaries is a vital first step, greater focus must also be placed on how to effectively integrate the various professionals, teams and services involved. This should be supported by robust structures and processes that enable seamless communication, coordinated care, and collaborative decision-making across all clinical services. The *Optimal Clinical Pathway for Adults: Motor Neurone Disease (MND)*, recently developed by the National Neurosciences Advisory Group (NNAG) (2023) in the UK, exemplifies a strategic effort to define the interconnected roles and responsibilities of the diverse services involved in providing MND patient care. It aims to promote integration across these services to reduce variability in care delivery and establish best practices that

enhance outcomes for patients and caregivers throughout the disease's progression. While this pathway offers valuable high-level guidance and may serve as a useful model for other healthcare systems to adapt, translating this model into everyday clinical practice requires concrete and practical implementation strategies.

Participants identified a range of personal attributes, such as problem-solving ability, adaptability, risk positivity, open-mindedness, and perspective-taking, as vital for managing the evolving and uncertain situations they encountered when working with plwMND. These qualities enabled them to remain responsive to the individual needs of the person, rather than becoming overwhelmed or avoidant of unexpected or unplanned changes or the multitude of presenting symptoms. These attributes strongly align with the provision of person-centred care, and appear to support professionals in tolerating ambiguity, risk and uncertainty when working with plwMND and their families. Research has found that while professionals working in the same clinical settings may experience and be exposed to the same clinical dilemmas and uncertainties, how they respond to these can differ, depending on what is known as their uncertainty tolerance (Reis-Dennis, Gerrity and Geller, 2021).

Uncertainty tolerance is defined as an individual's ability to cope with perceived ambiguity (Hillen *et al.*, 2017), and although this concept has been explored since the mid-twentieth century (Budner, 1962; Frenkel-Brunswik, 1949), its relevance to healthcare has only recently been emphasised (Han *et al.*, 2019). Research shows that HCPs demonstrate a wide range of cognitive, emotional, and behavioural responses to uncertainty, which may be adaptive or maladaptive depending on individual traits (e.g., cognitive flexibility, tolerance for ambiguity), social influences (e.g., team culture, peer support), and situational pressures (e.g., time constraints, resource limitations) (Yap, Johanesen and Walsh, 2023). Hillen's work highlights that these responses are not fixed but can be shaped by context and can significantly influence clinical decision-making, communication, and professional well-being (Hillen *et al.*, 2017). Evidence also suggests that more experienced clinicians tend to exhibit greater tolerance of uncertainty (Lawton *et al.*, 2019; Scott *et al.*, 2023) while difficulty in tolerating uncertainty increases risks of burnout and psychological strain,

particularly in high-pressure care environments (Iannello *et al.*, 2017; Di Trani *et al.*, 2021; Tamura *et al.*, 2025; Zybarth, Inhestern and Bergelt, 2025).

Several authors, including (Berger, 2015) and (Scott *et al.*, 2023), have outlined practical strategies to support clinicians in managing and communicating uncertainty. These include recognising and acknowledging one's own emotional responses and tolerance for ambiguity, discussing uncertainty with colleagues, problem-solving, and letting go of the need for absolute certainty. Other strategies emphasise shared decision-making with patients, clarifying goals over time, and respecting personal values and choices. Embedding these approaches to uncertainty management within training programmes and reflective practice may strengthen clinicians' tolerance of ambiguity, enhance confidence in complex decision-making, reduce psychological strain, and support clearer, more compassionate communication with patients and families navigating the realities of progressive neurological decline.

### 4.4.3 Moral Distress and Helplessness

HCPs are motivated by a fundamental commitment to improving the lives of others, and when circumstances prevent them from fulfilling this moral purpose, it can give rise to professional dissonance and distress (Austin, 2012). As stated in Austin (2012):

"*A professional is one who 'professes' the ability and intention to help others, promising in effect to help those who need it*" (Govier, 1997, p.79).

However, when systemic, institutional, or situational barriers obstruct this moral commitment, clinicians often experience moral distress (MD), the psychological discomfort of being unable to act in line with one's moral judgment, or to do what they believe is right (Austin, 2012; Currie and Laing, 2023) (1.2.3 Moral Distress). This dissonance between moral intentions and constrained actions can lead to frustration, helplessness, and a sense of moral compromise, ultimately eroding professional integrity and emotional well-being (Morley *et al.*, 2019). As Hanna (2004) highlights, such distress often stems from clinicians' empathy and commitment to alleviating patient suffering. This was strongly echoed in the present study,

participants described a deep sense of empathy and a compassionate drive to support plwMND, both in the present and in preparing them for what lay ahead. However, as described in Theme 3 many reported feelings of ineffectiveness or of being unable to make an impactful difference, often due to the complex interplay of factors such as systemic barriers, resource constraints, gaps in knowledge, relentless disease progression, and patient or family emotional and psychological burdens. The perceived inability to make a meaningful difference left some questioning their professional effectiveness, purpose, and even the value of their role. Despite variation across roles, experience, and settings, a unifying theme was identified as a profound sense of helplessness when they felt unable to meaningfully improve the lives or circumstances of plwMND or their families.

This reflects the growing recognition of MD across emotionally demanding areas of clinical practice, amplified by the aftermath of the Covid-19 pandemic (Mehlis *et al.*, 2018; Imbulana, Davis and Prentice, 2021; Latimer *et al.*, 2023; Jeong *et al.*, 2024). This phenomenon has received particular attention because of its impact on professional well-being, job satisfaction, and workforce retention (Maffoni *et al.*, 2019; Boulton *et al.*, 2023; Boulton and Farquharson, 2024). In the context of MND care, where clinical encounters are marked by irreversible and progressive cognitive, physical and often psychological decline, emotionally charged decision-making about end-of-life care, significant time and resource pressures and complex care pathways, the potential for MD is especially high. The challenges described by professionals in this study, provide insight into the potential drivers and consequences of MD in this field. Understanding the causes of MD in particular clinical contexts is important to inform the development of targeted supports and strategies, that can enable HCPs to deliver ethical and compassionate care that is aligned with their core professional values (Chapter 1: 1.2.3 Moral Distress).

The emotional burden of clinician helplessness in response to deep existential suffering has also been recognised in the literature, particularly when professionals are confronted with distress that lies beyond the scope of medical intervention (Back *et al.*, 2015; Pessin *et al.*, 2015). In this study, participants vividly conveyed this experience, highlighting how the limited treatment options available for MND often

left them feeling powerless in the face of profound patient suffering. Rattner (2020) similarly found that palliative care clinicians reported greater feelings of helplessness when confronted with non-physical forms of suffering, such as emotional or existential distress, compared to the confidence they felt in managing physical pain. While professionals recognised the value of presence, bearing witness and holding space for distress, they also spoke to the emotional weight of these encounters, often accompanied by a deep sense of helplessness when they could not offer tangible solutions that adequately alleviated the person's suffering. While demanding, professionals who felt able to engage in these emotive encounters often derived meaning from helping patients and families feel heard and supported, recognising the therapeutic power of listening and presence, in the absence of curative interventions. This reflects a shift from a "*fixing*" mindset to one that values accompaniment and emotional presence as therapeutic in itself (Arman, 2007; Kelly and McLeod, 2025). Back *et al*. (2015), proposed the RENEW (Recognising, Embracing, Nourishing, Embodying, and Weaving) framework as a tool for clinicians to reframe feelings of helplessness, and to view these not as a sign of failure, but as an expression of deep engagement and presence in care. As has been found in other studies, professionals who felt ill-equipped to manage either their own or the patient's emotional responses, reflecting challenges engaging in emotional labour, often reported withdrawing or limiting their engagement. This avoidance behaviour appeared to be driven by a profound sense of helplessness or perceived professional inadequacy (Boston, Bruce and Schreiber, 2011).

Compassion fatigue and secondary traumatic stress (STS) are related concepts that describe the emotional toll experienced by professionals repeatedly exposed to others' suffering (Pellegrini, Moore and Murphy, 2022). Originating in the 1990s, compassion fatigue was initially defined as the cost of caring for others in emotional pain and described the emotional exhaustion and diminished empathy experienced by helping professionals as a result of prolonged exposure to the suffering of others (Figley 1995). Over time, the concept evolved to incorporate elements of burnout and secondary traumatic stress (STS), defined as the stress resulting from indirect exposure to trauma through close contact with individuals who have experienced it.

Unlike burnout, which develops gradually due to chronic workplace stress, STS can occur suddenly and is often linked to empathic engagement with traumatic experiences (Chapter 1: 1.2.2 Compassion Fatigue). These concepts have become increasingly relevant for those working with palliative and progressive conditions and are amplified in the context of MD, where professionals form strong, trusting therapeutic relationships with patients and families during a highly emotive and challenging time, yet feel constrained in their ability to deliver the level of care they believe is required to effectively alleviate their burden, symptoms, or suffering (Maffoni *et al.*, 2019). The experiences described by professionals in this study suggest a high risk of compassion fatigue and secondary traumatic stress in the context of MND care, however, as outlined in Chapter 1 these aspects of professional well-being have received limited attention in the existing literature.

Emotional intelligence has increasingly been recognised as a critical capability for HCPs working in emotionally intense and relationally complex environments (Karimi *et al.*, 2021; Hashmi *et al.*, 2024; Sánchez Mora *et al.*, 2024). Research suggests that higher levels of emotional intelligence are associated with reduced burnout, compassion fatigue, and staff turnover (Năstasă and Fărcaş, 2015; Amir, Betty and Kenneth, 2019; Arnone, Cascio and Parenti, 2019), while also contributing to improved patient and family satisfaction with care and communication (Weng, 2008; Oyur Celik, 2017; Amini *et al.*, 2018). In this context, skills in emotional intelligence, commonly defined as the capacity to recognise, understand, and manage one's own emotions and respond appropriately to the emotions of others (Bru-Luna *et al.*, 2021), were identified as a valuable resource for clinicians. Core components of emotional intelligence, such as self-awareness, self-regulation, social awareness, and relationship management are especially relevant in clinical contexts where HCPs are required to navigate emotionally charged interactions, ethical dilemmas, and uncertain outcomes (Antonopoulou, 2024). Encouragingly, several studies have demonstrated that emotional intelligence is not a fixed trait but can be strengthened through targeted interventions, including psychoeducation, mindfulness, experiential learning, reflective practice, and team-based approaches (Powell *et al.*, 2024; Salem, Hashimi and El-Ashry, 2025). These findings suggest that incorporating

emotional intelligence training into clinical education, professional development, and workplace support systems may enhance clinicians' emotional resilience, improve their ability to navigate emotionally intense conversations, enhance professional well-being and ultimately contribute to more positive experiences of care for patients and families.

### 4.4.4 Neuropalliative Care Approach

In the context of progressive, incurable neurological conditions such as MND, HCPs may find it difficult to recognise the impact or value of their work when traditional clinical indicators, such as improved survival, disease reversal, or functional restoration do not apply. This may be another contributing factor to the feelings of futility and helplessness described by participants, particularly in relation to their inability to significantly alter the course of the disease. Adopting a palliative approach to care may offer an important reframing of what constitutes "*successful*" care in this context. Rather than focusing on curative or restorative outcomes, emerging neuropalliative care models prioritise person-centred goals, a focus on quality of life, effective symptom management, psychological and emotional support, and the preservation of autonomy and dignity (Grossman *et al.*, 2023; Kluger *et al.*, 2023). This shift not only aligns care more closely with what matters to patients and families but may also help professionals find deeper meaning and value in their work. A critical, but often under-recognised, benefit of competence in applying a palliative care approach is its potential to alleviate clinicians' sense of helplessness by emphasising the tangible impact of holistic, supportive, and rehabilitative care, even in the face of inevitable disease progression (Gill *et al.*, 2024).

Yet, as Grossman *et al.* (2023) observe, current outcome measures often fail to capture the complex and evolving needs of people with progressive neurological conditions. Neurology based assessment tools rarely account for the deteriorating and palliative nature of these diseases, while traditional palliative outcome measures are not tailored to the complex symptom management and care needs unique to neurological populations (Creutzfeldt *et al.*, 2018). Although promising

tools and frameworks are emerging (Gao *et al.*, 2016; Dillen *et al.*, 2019; McDool *et al.*, 2024) further research is needed to validate and implement these in diverse care contexts (Grossman *et al.*, 2023; Lau *et al.*, 2025). Wider literature has shown that recognising the value of one's work in alleviating suffering and improving quality of life is protective against distress and burnout (Moreno-Milan *et al.*, 2019; Romão *et al.*, 2025), highlighting the importance of effectively measuring and highlighting when these outcomes have been successfully achieved.

It is well established that palliative care principles should be embedded across health and community services and introduced early, ideally from the point of diagnosis in life-limiting conditions (Dalgaard *et al.*, 2014; Vanbutsele *et al.*, 2018). However, this study and previous research show that even specialist palliative care clinicians frequently report uncertainty and reduced confidence when supporting progressive neurological conditions, reflecting distinctive challenges such as unfamiliar and fluctuating symptom profiles, complex communication needs, profound psychological distress, and intensive physical care requirements (Gofton *et al.*, 2018; Silveira and Forte, 2022; Wiblin, 2024). Although some efforts have been made in Ireland to integrate neurology and palliative care, for example, through collaborative initiatives led by the Neurological Alliance of Ireland and the Irish Hospice Foundation, service delivery remains fragmented, with marked regional variations in access, collaboration, and referral practices between services. Findings from this study underscore the need for a more coordinated, equitable, and adequately resourced approach to the provision of training and the effective delivery of neuropalliative care across all health and social care services.

### 4.4.5 Supporting and Sustaining Professionals in MND Care

Theme four highlights a number of factors that were perceived as both helpful and protective for professionals working in this emotionally demanding area of clinical practice. Support needs are likely to vary based on the proportion of professional's time spent working with MND patients. However, regardless of service, all professionals in this study acknowledged the emotional toll and the need for

support to enable them to remain engaged and involved throughout the patient's illness trajectory.

Each service recognised interpersonal supports including team cohesion, formal and informal peer support and opportunities for team reflection and debriefing as valuable to them in processing the difficult situations they were exposed to. However, most also acknowledged that such support was not routinely embedded in their practice and was often deprioritised by the teams or organisations they worked in. Therefore, debriefing with colleagues happened on an ad hoc basis and only if there happened to be somebody available to talk. To address this, efforts should also focus on integrating dedicated time for collegial support and fostering a workplace culture where peer support and recognition are embedded as integral parts of daily practice. Services should invest in strengthening team dynamics, ensuring strong working and supportive relationships between members, with a focus on building psychological safety and trust within the teams of professionals supporting these individuals and families (Clark, 2009). Future research should also explore the implementation and impact of structured interventions, such as Schwartz Rounds, Balint groups, debriefing sessions, and reflective practice forums, that offer clinicians a safe, confidential space to process the emotional demands of their work. Such interventions have demonstrated effectiveness in other complex areas of practice but have yet to be considered for those working with the unique complexities of progressive neurological conditions (Maben *et al.*, 2021; Scott, O'Curry and Mastroyannopoulou, 2022; Neil *et al.*, 2023; Ng *et al.*, 2023). Evaluating the effectiveness of these approaches in reducing emotional burden, enhancing job satisfaction, and mitigating staff turnover would be of particular value. Consideration should also be given to delivering these interventions across services, particularly for professionals who have worked together on especially challenging cases. MND charity organisations may be well-placed to help coordinate and extend these support services across teams and settings, ensuring that resources are also accessible to those who interact with plwMND less frequently but still require emotional and professional support.

Some professionals also highlighted that having temporal flexibility within their work schedules, such as the ability to take breaks after emotionally intense interactions, or manage the pace of their workload, was instrumental in helping them cope with the emotional demands of their roles. In addition, feeling able to openly express when aspects of a person's care felt overwhelming, and to request additional support without fear of judgment, was valued. These experiences highlight the importance of cultivating a workplace culture, with approachable leadership, that recognises and actively supports the emotional weight of this work, rather than assuming that frequent exposure alone equips professionals to manage it independently. For managers and organisational leaders, this further underscores the need to acknowledge the emotive nature of this work and to be particularly mindful of certain cases and patient circumstances that can be especially triggering for certain professionals.

Developing a knowledgeable, committed and healthy workforce should be a priority for all services responsible for delivering MND care, due to the value patients and families place on competent and consistent professional care and the impact of professional presence and support on both their emotional well-being, perceived quality of life, anxiety about the future and experiences of grief (Pinto *et al.*, 2021). The findings in this study regarding the factors that help sustain professionals in these roles are therefore noteworthy and warrant careful consideration. An interesting finding was the value participants placed on the learning opportunities and skill development they experienced from working with the complexities of MND patient care and with a wide number of MDT colleagues. Opportunities for continuous learning and professional development were highly valued by participants in this study, who emphasised the importance of staying informed about current and emerging evidence, clinical practices, and evolving approaches to care for plwMND and their families. Having access to up-to-date training, condition-specific knowledge, and interdisciplinary learning may not only enhance professionals' confidence in clinical decision-making but could also help to reduce feelings of stress and uncertainty, particularly for groups of professionals who encounter the condition less frequently. Moreover, investing in

accessible learning and networking opportunities may play a key role in supporting staff retention, preventing burnout associated with clinical uncertainty, and sustaining a motivated and resilient workforce capable of navigating the multifaceted challenges associated with providing MND care.

In addition, to organisational efforts, the literature suggests that individual level supports are also necessary to address and support HCP well-being (Catapano *et al.*, 2023). This was echoed by the participants in this study who recognised the importance of self-awareness, monitoring their own emotional responses, recognising signs of emotional exhaustion and burnout, being able to create a safe distance and balance between work and personal life and having a focus outside of work that included self-care activities, hobbies and social outlets. Ensuring that professionals have their own personal well-being plans in place is potentially an important role for those in management and supervisory positions.

Vicarious resilience can offer an important counterbalance to the more commonly discussed risks of compassion fatigue and vicarious trauma in challenging healthcare settings (Killian *et al.*, 2017). Originally introduced in the context of working with survivors of political violence and war trauma (Hernández, Gangsei and Engstrom, 2007), the concept has recently been extended to various areas of healthcare practice, including oncology and palliative care (Grauerholz *et al.*, 2020; Tsesmelis Piccolino, 2022). It describes the process through which clinicians derive meaning, strength, and personal growth by witnessing the resilience of the patients they work with (Hernandez-Wolfe, 2018). As outlined in Theme 4 In this study, professionals described deriving profound inspiration and admiration, from the remarkable adaptability and resilience that plwMND and their families demonstrated in the face of adversity and relentless loss. Witnessing this resilience was described as a vicarious source of strength and resilience for professionals themselves.

Rather than viewing exposure to suffering merely as a risk factor for burnout or secondary traumatic stress, vicarious resilience highlights the potential for growth and a deep sense of professional meaning and fulfilment (Killian *et al.*, 2017). The cultivation of vicarious resilience in this context may be supported through

multiple avenues, including effective and robust clinical supervision (Tsesmelis Piccolino, 2022), creating opportunities for professional learning and development, structured opportunities for reflective practice (Grauerholz *et al.*, 2020), and the intentional sharing of positive feedback or messages of gratitude from patients and bereaved families. Emerging research suggests this process may contribute to improved well-being and professional sustainability, though further empirical validation is needed (Hernandez-Wolfe, 2018). While this may not diminish the emotional toll of this work, the intentional cultivation and discussion around vicarious resilience could serve as a vital protective factor, supporting professionals to remain engaged, compassionate, and connected to the meaning in their work.

## Study Strengths and Limitations

This is the first study to explore HCPs' experiences of working with MND in Ireland, and, to our knowledge, the first qualitative study to include perspectives from all key multidisciplinary team members and services involved in providing MND care. This was an important aim for this study, as our scoping review, identified that most of the research to date has focused on very specific groups of professionals and niche aspects of MND patient care such as professionals experiences of involvement the process of withdrawal of non-invasive ventilation (Baxter *et al.*, 2013; Chapman, Bayes and Sim, 2021). The broader focus of this exploratory study therefore allowed for more comprehensive identification of some of the key stressors, challenges and rewards experienced by all HCPs interacting and supporting individuals and families living with MND, despite their professional background, role or experience level. Flexibility in the mode of focus group facilitation was also an important strength in this study as it enabled professionals from each of the target services to participate at their own convenience and likely contributed to the strong representation achieved across all targeted services.

To ensure quality and rigour, this study followed the principles of reflexive thematic analysis as outlined by Braun and Clarke (2019, 2024). The analysis was conducted

with an awareness of the researcher's active role in theme development. Transparency was maintained through detailed documentation of analytic decisions and regular collaborative discussions among the research team. Themes were developed inductively through deep engagement with the data, aiming for richness, nuance, and coherence, rather than representational consensus or coding reliability. This approach ensured that the analysis remained consistent with the epistemological underpinnings of reflexive thematic analysis, prioritising depth of meaning and interpretive insight over procedural objectivity.

While a diverse and representative sample was achieved, only one medical professional took part. Nurses were the most highly represented group, alongside a broad representation of allied health professionals. As a result, some of the clinical situations and challenges described may not fully capture the unique pressures faced by medical professionals, particularly in the context of a condition where medical intervention is intensely limited. The medical profession often carries significant responsibility, which is associated with a higher risk of burnout (Kumar, 2016); however, they are often less likely than other professional groups to report distress and seek out emotional or peer support (Zaman *et al.*, 2022). Their underrepresentation in this study may reflect a self-selection bias or reluctance to participate due to awareness of power dynamics within multidisciplinary teams. These are therefore an important group to consider and target for recruitment in future phases of this research, to ensure their perspectives and support needs are adequately understood and addressed. It is important to acknowledge that these findings are specific to the Irish context and reflect the challenges encountered when working with this population within Ireland's health and social care system. Given the substantial variation in how healthcare services and systems are organised across Europe and internationally, many of the systemic and organisational challenges identified in this study may not be reflective of those in other areas or regions.

## 4.5 Conclusion

This reflexive thematic analysis illuminates the complex emotional and relational landscape navigated by HCPs delivering care to plwMND across the illness trajectory and throughout the Irish healthcare system. Through exploring their experiences, it became evident that while clinicians are often deeply committed to providing compassionate and responsive care, they are also frequently challenged by feelings of uncertainty, emotional burden, helplessness and system level constraints. Importantly, the findings highlight not only the challenges professionals face but also experiences of personal and professional growth and vicarious resilience, that help sustain their ability to provide empathic care for these patients and families. The demanding nature of this work was additionally balanced by the perceived meaningfulness of their roles, connected to making a difference in the lives of the patients and families they supported. In addition to recommendations for organisational and system level changes, this study identified a range of suggestions for professional education and development and supports aimed at helping professionals to remain engaged in supporting individuals and families living with MND, while simultaneously safeguarding their own personal and professional well-being. These included access to effective clinical supervision, regular opportunities for peer and team reflection or debriefing, strong and supportive team dynamics, support with managing complex relational boundaries, and the ability to maintain a healthy separation between work and personal life.

The next chapter will outline the development and findings from an international survey of the MND workforce in Europe. This survey was designed to measure the impact of working amidst the emotional and ethical challenges, that were vividly described in this qualitative study on the psychological well-being of HCPs involved in the delivery of MND patient care. It will also build on some of the insights generated here by drawing on a larger sample of HCPs to explore the factors they perceive as most helpful and supportive for them in this work.

# Chapter 5: Phase Three - Cross-Sectional Online Survey

## Moral Distress, Professional Quality of Life, Retention, and Resilient Coping Among Healthcare Professionals Working in MND Care: A European Cross-Sectional Online Survey

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**Author Contributions:** **MW designed and developed the survey tool, completed the recruitment process, collected and analysed the data and wrote the report/manuscript**. AC and MG reviewed the survey tool and the final analysis and reviewed, edited and approved the final version of the report/manuscript.

## Abstract

**Introduction:** The issue of moral distress, and its potential impact on the professional quality of life of healthcare professionals working with MND, has received limited attention, despite the presence of numerous risk factors in this cohort. The professional quality of healthcare professionals in this field is also underrepresented in the literature, as well as the supports and resources needed to sustain their capacity to deliver compassionate, consistent, and high-quality care to individuals affected by such a devastating, progressive and incurable condition.

**Aim:** To assess the prevalence, intensity, and contributing factors of moral distress, measure professional quality of life, coping resilience capacity and identify supports and resources that promote well-being and sustainability among healthcare professionals working with MND across Europe.

**Method:** A cross-sectional online survey collected quantitative data and open-text responses from professionals working in MND services across Europe. Measures included the Moral Distress Thermometer, the Professional Quality of Life Scale (ProQOL-5), and the Brief Resilient Coping Scale (BRCS). Quantitative data were analysed using descriptive and inferential statistics, while open-text responses were analysed using content analysis.

**Results:** Data from 240 respondents were analysed, representing 17 European countries and 11 professional backgrounds. 67% of respondents identified that moral distress resonated with their experience of working with MND, and these respondents were more likely to be considering leaving their job, both in the present or the past because of factors related to working with MND. The intensity of MD experienced was associated with reduced professional quality of life (burnout ($\beta$ = 0.106, $p$ <0.05) and secondary traumatic stress ($\beta$ = 2.881, $p$ <0.001)). Organisational/system level factors were the most frequently experienced and distressing barriers to providing effective MND care across all professional groups. On the ProQOL-5, average levels of burnout were moderate, secondary traumatic stress was low, and compassion satisfaction was high. Compassion satisfaction was negatively associated with burnout ($\beta$ = - 0.438, $p$ <0.001) but not secondary

traumatic stress ($\beta$ = -0.004, $p$ = 1.000). The majority of respondents had a moderate level of resilient coping, but this was not strongly associated with negative well-being outcomes. Informal collegial support and working within a supportive multidisciplinary team were the most often identified sources of support.

**Conclusion:** This study highlights moral distress as an issue affecting the professional quality of life and retention of HCPs working with MND in Europe. Organisational/system level factors were identified as the most commonly experienced and distressing barriers to providing care that aligned with professional or ethical standards. Healthcare services, organisations and teams should consider how services can be flexible, accessible, and responsive to the evolving needs of plwMND, ensuring professionals feel supported and empowered to meet their needs effectively. Compassion satisfaction is high in this population but may not protect HCPs from the impact of secondary exposure to patient suffering and while resilience was moderately high, it also was not highly protective against negative well-being outcomes. Professionals working with these patients, should therefore have opportunities to reflect on the moral, ethical, and emotional challenges of their work, and have access to support from management, colleagues, and peers when needed.

## 5.1 Introduction

HCPs working with patients and families affected by MND can experience both personal and professional challenges, as well as moments of deep reward (Walls *et al.*, 2024).

Findings from the qualitative phase of this research (Phase 2: Qualitative Focus Group Study) revealed that many professionals felt unable to provide the level or type of care they believed was necessary to fully meet the needs of patients and families. Such situations frequently gave rise to feelings of helplessness, ineffectiveness, anxiety, and frustration. Similar experiences were reported in a recent UK study, where organisational barriers and systemic limitations were among the greatest challenges identified by professionals working with MND, contributing to exhaustion and the sense of "*not being able to provide the care they wanted to provide*" (Chau *et al.*, 2025, p.9). These findings underscore the profound emotional and moral challenges inherent in MND care and highlight risk factors for moral distress (MD).

The concept of MD is discussed in detail in Chapter 1 of this thesis. Although related to other dimensions of professional well-being, MD is distinct in that it arises when professionals are constrained from acting in alignment with their ethical or moral beliefs, thereby compromising their ability to deliver care consistent with those values (Morley *et al.*, 2019). Initially identified among critical care nurses, MD has since been recognised across a range of healthcare disciplines (Houston *et al.*, 2013; Whitehead *et al.*, 2015), particularly in contexts involving prolonged exposure to patient suffering (Rushton, Kaszniak and Halifax, 2013), complex end-of-life decisions (St Ledger *et al.*, 2013; Mehlis *et al.*, 2018), and highly demanding or resource-limited environments (Wall, Austin and Garros, 2016).

A comprehensive understanding of the ethical dilemmas, clinical circumstances, and contextual factors that give rise to MD across healthcare settings is essential for developing strategies to manage and, where possible, mitigate its impact (Currie and Laing, 2023). Epstein *et al.* (2019) conceptualise the contributors to MD as "*root causes",* typically operating across three interconnected levels: the patient level (e.g., pressure to continue aggressive treatment at the end of life despite limited

benefit and increased suffering), the unit level (e.g., staffing shortages or resource constraints that compromise safe and compassionate care), and the system level (e.g., institutional policies or structural barriers that restrict access to essential services). While this framework effectively captures many of the external drivers of MD, it has been critiqued for underrepresenting the influence of internal or personal factors that shape how individuals experience and respond to ethically challenging situations in practice (Beadle *et al.*, 2024). Scholars such as Rushton (2017) and Fourie (2015) emphasise that internal constraints, including self-doubt, perceived powerlessness, and knowledge gaps, can inhibit professionals from acting in alignment with their moral or ethical judgments, even in the absence of explicit external barriers. The distinction between external and internal sources of MD aligns closely with findings from earlier phases of this research, in which professionals described comparable barriers to providing the quality or type of care they believed would best support plwMND. However, despite the clear presence of risk factors, MD and its specific contributors have not yet been explicitly examined among professionals working in MND services.

This study aims to address this gap by examining whether MD is perceived as a significant concern among the MND workforce, the extent to which it affects professionals, the factors that contribute to its development, and whether particular professional groups are disproportionately impacted. It will also explore the relationship between MD and other dimensions of professional quality of life and consider its potential influence on professionals' intentions to remain in or leave their roles within MND services. The detrimental impact of MD on retention and turnover intention has been widely documented in other high-stress clinical contexts (Austin, Saylor and Finley, 2017; Kim, Kim and Oh, 2023; Delgado-Ron *et al.*, 2024; Cerela-Boltunova, Millere and Nagle, 2025) but remains undocumented in MND care.

In addition to the risk of MD, professionals working with MND are continually exposed to the emotional toll of repeated loss, death, grief and suffering. In Phase Two (Chapter 4) of this research, many professionals in specialist services noted that colleagues often avoided working with MND due to the perceived emotional intensity of this work, and the perceived demands associated with managing an MND

caseload. Likewise, those in non-specialist roles viewed that working solely in MND care would be too emotionally demanding, citing fears of exhaustion and burnout. Despite the emotionally charged nature of this work and the deep, sustained relationships that are often formed with patients and families, the professional quality of life of those working in MND services remains significantly under-represented in the literature (Harris *et al.*, 2018; Walls *et al.*, 2024).

The well-being of HCPs likely has direct implications for workforce sustainability and the quality of care received by plwMND and their families. PlwMND and their families depend on stable, skilled, and compassionate professional support throughout the trajectory of their illness. Service continuity and the ability to maintain therapeutic relationships over time are highly valued by patients, yet inconsistencies in care provision are widely reported (Pinto *et al.*, 2021). The reasons behind these inconsistencies are not fully understood but may be linked to the challenges professionals face in maintaining engagement amid cumulative emotional and ethical strain. Chau *et al.* (2025) identified staffing shortages within multidisciplinary teams and external services as key barriers to delivering consistent, high-quality care. However, no studies to date have directly explored intentions to leave among professionals working in MND care or included participants who have left such roles because of the challenges associated with this work. Understanding the factors that influence retention and turnover in this workforce is critical to the sustainability of services and to ensuring that plwMND receive consistent, high-quality, and compassionate care across the full trajectory of their illness.

While it might be assumed that that professionals in specialist roles are at greater risk of emotional strain due to increased exposure to complex and demanding cases, many in this field describe their work as deeply rewarding (Gamskjaer, Werlauff and Handberg, 2022; Hansen, Burton-MacLeod and Schellenberg, 2024). In the qualitative phase of this research, professionals working in MND specific roles, were more likely to describe the rewarding aspects of this work, which may be due to their accumulated knowledge, clinical expertise, and experience, factors that appear to act as protective, enhancing both their perceived effectiveness and their ability to make a meaningful difference in the lives of patients and families. Similarly,

Bromberg, Schenkenberg and Brownell (2011) found that among ALS clinic managers and neurologists, greater clinical experience was associated with lower stress levels for the majority of participants.

However, despite these insights, a significant gap remains in the literature, particularly within the European context, regarding the professional well-being and quality of life of HCPs working with MND. While Bromberg, Schenkenberg and Brownell's (2011) study examined general stress, no research to date has specifically focused on moral distress, and few very recent studies have explored the broader dimensions of professional quality of life within this workforce (Hansen, Burton-MacLeod and Schellenberg, 2024; Chau *et al.*, 2025). This study seeks to address this gap by examining moral distress and its impact on professional quality of life, while also considering the potential protective role of factors such as clinical experience, satisfaction in helping, and resilience in buffering against negative psychological and occupational outcomes and supporting continued engagement in MND care.

Earlier phases of this PhD research identified a range of factors perceived as helpful and supportive by those providing MND care, across both MND specific and non-specific roles, in Ireland. These supports spanned organisational (e.g. adequate staffing, access to training, supervision), team-based (e.g. peer support, multidisciplinary collaboration), and individual levels (e.g. personal coping strategies, professional development opportunities). While these findings offered valuable insight, it is important to obtain a range of views from HCPs over and above the Irish context. This study aims to build upon that foundation by identifying factors that are considered supportive and helpful by professionals working with MND across various European healthcare systems. Notably, there remains a scarcity of research that directly seeks the perspectives of HCPs regarding the supports they need to effectively carry out their roles in this complex field. Understanding these needs is essential, not only to enhance professional well-being and retention, but also to ensure the delivery of consistent, high-quality care to patients and families affected by MND across different care settings and countries.

### 5.1.1 Aim and Objectives

#### Aim

The aim of this study is to explore the emotional, psychological and professional well-being of healthcare professionals providing care to individuals and families affected by MND across Europe. Specifically, the study seeks to examine the prevalence and determinants of moral distress, professional quality of life and resilient coping within this workforce, and to identify individual, professional, and organisational factors that may influence retention, psychological well-being, and the capacity to sustain compassionate, high-quality care for MND patients and families.

#### Objectives

1) To determine rates of turnover intention and absenteeism, and to identify factors influencing these outcomes within this workforce.
2) To measure the occurrence of MD and clinical situations that may contribute to experiences of MD in MND care.
3) To determine the level of MD experienced and factors associated with its intensity.
4) To measure the professional quality of life of healthcare professionals working with MND using the constructs of burnout, compassion fatigue and compassion satisfaction.
5) To examine relationships between moral distress, professional quality of life, resilient coping, demographic characteristics, and work-related factors influencing the well-being of healthcare professionals in MND care, with an a priori expectation that moral distress will be positively associated with burnout and secondary traumatic stress and negatively associated with resilient coping and compassion satisfaction.
6) To measure the coping and resilience capacity of healthcare professionals working with MND and identify factors perceived as helpful or supportive in their work.

## 5.2 Methods

### 5.2.1 Study Design: Cross-Sectional Online Survey

This study used a cross-sectional design and an online survey method, to collect both quantitative data and open-text responses from HCPs working in services for plwMND across Europe.

A cross-sectional survey design is well suited to exploratory research, allowing for the efficient collection of data on a broad range of variables from a large sample (Maier *et al.*, 2023). This method is particularly effective in new or under-researched areas for identifying potential patterns and associations, and for establishing foundational relationships that can generate insights to inform future, more targeted research (Spector, 2019; Capili, 2021). Alternative approaches, such as longitudinal or experimental designs, were deemed unsuitable due to the nature of the study objectives. Longitudinal studies, which track participants over time to establish cause-and-effect relationships, require a clear understanding of the timeframe within which causal relationships may occur (Taris and Kompier, 2014). In this case, the timeframe for potential causal relationships was uncertain and likely occurred over an extended period, making it challenging to implement a longitudinal study effectively. Experimental designs, which typically involve manipulating variables to establish causality (Em, 2024), were deemed unsuitable for this study as its aim was to observe and understand the effects of experiences that had already occurred prior to data collection. Since these experiences were neither practically nor ethically replicable or controllable, an experimental approach would not effectively capture the complexity of these past events or their consequences. Therefore a cross-sectional design study was deemed most suitable, as the temporal sequence of variables was not yet known and could not be easily established (Wang and Cheng, 2020).

The cross-sectional nature of the design is advantageous for establishing prevalence rates and identifying statistical associations, but limits the ability to draw conclusions about causal relationships (Spector, 2019). Since data are collected at a single time point, the directionality of observed associations cannot be determined, and temporal sequencing cannot be established, making it difficult to distinguish

whether certain factors are causes or consequences of outcomes like professional distress or well-being (Roberts, Ashrafzadeh and Asgari, 2019). Although statistical controls can account for some confounding, the influence of unmeasured or residual confounding variables cannot be entirely ruled out (Kahlert *et al.*, 2017). Nonetheless, given the exploratory aims of this study, the cross-sectional design is appropriate and provides a meaningful basis for identifying potential risk and protective factors influencing the professional well-being of HCPs working in MND care.

The use of an online survey method also offered several methodological advantages for this study. It enabled efficient distribution of the data collection tool across a wide geographic area, facilitating access to a broad and diverse sample of HCPs working in MND care throughout Europe (Regmi *et al.*, 2017). Additionally, the online format supported both anonymity and participant convenience. Online surveys provide a degree of anonymity that may encourage more honest and reflective responses to sensitive questions such as ethical challenges, emotional well-being, and moral distress (Murdoch *et al.*, 2014). Furthermore, the flexibility of the online approach allowed participants to complete the survey at a time and place that was convenient for them. Respondents could take as much time as needed to consider their responses and even complete the survey in multiple sessions if required. These features can contribute to greater participant comfort and hence data quality (Ball, 2019).

Another key advantage of the online survey method is its flexibility in question design and delivery. It supports a wide range of question formats, including dichotomous, multiple-choice, Likert scales, and open-ended questions, allowing for the integration of both quantitative and qualitative data within a single instrument (Regmi *et al.*, 2017; Braun *et al.*, 2021). Adaptive logic can be used to automatically skip irrelevant questions or to only display specific questions for certain sub-groups, thereby enhancing the relevance and clarity of the survey for each respondent. Features such as forced responses help minimise missing data and improve the completeness and reliability of the dataset. Online survey platforms such as the Qualtrics platform used in this study, offer a high degree of customisation, enabling

a more efficient and user-friendly data collection process. In this study, these features were used to tailor question pathways based on participants' current or former employment in MND services and their previous responses in specific sections, thereby improving both the relevance of the survey experience and reducing respondent burden.

Online surveys often report low response rates (Ball, 2019), typically between 20-40%, which can reduce the representativeness of the sample and external validity of the findings (Wu, Zhao and Fils-Aime, 2022). Individuals may ignore or abandon online surveys due to lack of interest, time constraints, or survey fatigue, particularly if the invitation is impersonal or the survey appears lengthy or irrelevant (Fan and Yan, 2010). Lack of personal engagement with the research team, may also reduce motivation to engage (Wu, Zhao and Fils-Aime, 2022). Therefore, a number of evidence-based strategies were employed during the development of this survey to enhance the response rate and data quality (Shiyab *et al.*, 2023). The invitation email was brief but informative, clearly outlining the purpose, benefits of participation, estimated completion time, and an overview of survey sections to ensure participants were well informed prior to engaging. Dissemination through a trusted and familiar organisation added a sense of legitimacy and personal relevance. Furthermore, pilot testing and feedback from professionals working in the field informed the survey design, ensuring relevance and reducing the risk of question ambiguity, survey fatigue, or dropout (Wu, Zhao and Fils-Aime, 2022; L'Ecuyer *et al.*, 2023; Shiyab *et al.*, 2023). Progress indicators were also incorporated to give participants a clear sense of advancement, helping to sustain engagement and minimise late-stage attrition (Park, Lee and Lee, 2022). Finally participating organisations sent either two or three reminder emails to professionals who received the initial invitation link (Koitsalu *et al.*, 2018; Barnhart, Reddy and Arnold, 2021). These strategies were felt to be effective in the current study as missing data were negligible, and 84% of participants who started the survey completed it in full.

### 5.2.2 Survey Development

The survey questions were informed by the earlier research phases, scoping review and focus group study. Expert opinion from a range of HCPs (Physiotherapist, Occupational Therapist, Psychologist & Speech and Language Therapist), working in specialist MND roles was sought and the online survey was pilot tested with 5 HCPs from the UK, Ireland and Denmark prior to distribution. The inclusion of non-native English speakers was an essential step at the development stage, given that the survey was distributed internationally but exclusively in the English language. The survey was hosted on Qualtrics$^{xm}$ online survey platform. Full survey questions can be found in Appendix L.

### 5.2.3 Question Development and Measurement Tools

### A. Demographic, Work-Related Data, Turnover and Absenteeism

Respondents were first asked demographic, work-related questions and about turnover intentions and absenteeism (Table 5.1).

**Table 5.1:** Demographic, Work-related, Turnover and Absenteeism Questions

| **Demographic and Work-Related Questions** |
|---|
| Do you work full-time/part-time? |
| On average what percentage of your working week is working with individuals living with ALS/MND? |
| What is your professional role with individuals living with ALS/MND? |
| What gender do you identify as? |
| Which age category do you belong to? |
| What country do you work in? |
| In what setting(s) do you work with individuals living with ALS/MND? |
| How many years of experience do you have working with ALS/MND? |
| **Turnover and Absenteeism:** |
| In the past two years, have you left a job as a healthcare professional because of factors related to working with ALS/MND? |

Are you **currently** considering leaving or changing your job because of factors related to working with ALS/MND?

Have you **ever** considered leaving or changing your job because of factors related to working with ALS/MND?

Have you **ever needed to take time off work** because of factors related to working with ALS/MND?

Do you see yourself continuing to work with ALS/MND in the future? Why/why not?

Open ended questions were also used in this section to gain further insights into why some respondents had considered leaving or changing positions, what they were considering doing instead, reasons for absenteeism and reasons why they did or did not see themselves continuing to work with MND in the future.

## B. Moral Distress

### B.1 Moral Distress Description and Clinical Scenarios

Respondents were first asked a dichotomous yes/no question about whether they had previously heard of the concept of moral distress (MD). They were then presented with a brief description of the concept, that was developed by the research team and asked whether it resonated with their experience of working with MND. Response options were 'yes', 'no', or 'not sure'.

The Measure of Moral Distress for Healthcare Professionals (MMD-HP) (Epstein *et al.*, 2019) is currently the most widely used tool across disciplines to identify situations that can cause MD in HCPs. However, as the aim of this study was to identify situations specific to working with an MND population, the items included in this tool did not accurately reflect the unique ethical challenges experienced by those working with these patients and families. Therefore, 24 clinical situations were developed from the qualitative data gathered in phase 2 of this research to reflect barriers and constraints to providing desired or perceived adequate levels of care for people and families living with MND. These were categorised at the professional level, patient or condition level, family level, team and wider service or organisational level. Feedback

was received on the wording and relevance of these statements to working with an MND population from specialists working in the field prior to distribution. Respondents were asked in this section to indicate whether they had experienced each of these 24 situations in their work with plwMND (yes/no). For the clinical scenarios endorsed "yes" they were then asked to select the top 5**,** that they found most distressing. An optional open-text box was provided for additional comments.

An internal consistency analysis of responses within each of the five categories indicated that the reliability of individual domains ranged from low to moderate: Professional Level α = 0.58; Patient/Condition α = 0.55; Family α = 0.56; Team α = 0.68; and Organisational α = 0.59. In contrast, the overall internal consistency of the total scale was strong (α = 0.85), suggesting that, while the tool is reliable as a whole, the consistency of individual domains requires further improvement. Therefore, although this tool provides a valuable foundation for identifying clinical situations that may contribute to MD among professionals working with MND, further refinement and validation are needed before it can be confidently applied in future research or clinical practice.

## B.2 The Moral Distress Thermometer

The Moral Distress Thermometer (MD Thermometer) (Wocial and Weaver, 2013) measures the '*real-time'* intensity of MD at a single time point[2]. It is a single item, 11-point visual analogue scale, with scores ranging from 0-10. Six descriptors are provided at every second interval, ranging from 0 = "*None*" to 10 = "*Worst Possible*", helping respondents to anchor the intensity of MD experienced in the previous two weeks. The tool also provides a standard definition of MD: "*Moral distress occurs when you believe you know the ethically correct thing to do, but something or someone restricts your ability to pursue the correct course of action"* (Wocial and Weaver, 2013). In the survey respondents were asked to reflect on their clinical practice over the past two weeks and indicate, on the thermometer scale, the level of MD they experienced specifically in relation to their work with the MND population.

[2] Permission was obtained from the author Dr Lucia Wocial, to use the MD Thermometer in this study.

The MD Thermometer was chosen for its brevity, ease of online administration, and numeric scale, that allowed for statistical analysis to explore the relationship between the intensity of MD experienced and other professional well-being metrics included in this study. Based on Wocial and Weavers' (2013) results, this instrument demonstrated adequate convergent and concurrent validity with the Moral Distress Questionnaire (2009)(Eizenberg, Desivilya and Hirschfeld, 2009), which was the most widely established measure of MD at the time. In this current study, the intensity of MD reported on the MD thermometer scale was positively correlated with the number of potentially morally distressing statements respondents selected '*yes*' to experiencing in section B1 ($r_s$ = 0.37, $p$ < 0.0001). Those who selected '*yes*' to resonating with the description of MD provided in section B1 of the survey, also had significantly higher scores on the MD Thermometer scale than those who selected 'no' (Z = -5.47, adjusted $p$ < 0.001), or 'not sure' (Z = -2.93, adjusted $p$ = 0.01). Therefore, while the MD Thermometer can be criticised for its simplicity, as a single item tool in capturing the complexity inherent in the experience of MD. It was felt to be a reliable and useful add on measure in this current study, when considered in conjunction with the data collected in relation to the potential causes and consequences of MD.

All other tools identified and considered to measure MD in this study and the reasons for exclusion can be found in Appendix M.

## C. The Professional Quality of Life Scale – Version 5

The Professional Quality of Life Scale version 5 (ProQOL-5) is designed to assess the impact of caregiving on professional well-being. It is used to measure both the positive and negative effects of working in helping professions and with people who have experienced extremely stressful events (Stamm, 2010)[3]. The ProQOL-5 was selected as measuring both the positive and negative aspects of professional well-being in the context of providing MND care, was important to understand as per the aims of this study. The ProQOL-5 is also often used in research on moral distress

[3] Permission was obtained from the ProQOL office to use the ProQOL version 5 in this study.

(MD) across various clinical settings (Whitehead *et al.*, 2015; Austin, Saylor and Finley, 2017; Zare-Kaseb *et al.*, 2025). As discussed in Chapter One of this thesis, while these are distinct concepts, a number of studies have demonstrated that MD is positively associated with compassion fatigue (burnout & STS), while emerging evidence suggests a potential protective role for compassion satisfaction (Dodek *et al.*, 2021).

The ProQOL-5 measures three key factors: compassion satisfaction, burnout, and secondary traumatic stress, providing a nuanced understanding of professional well-being (Figure 5.1) (Stamm, 2010). Each factor is comprised of 10 questions each. The positive aspects of caregiving are indicated by compassion satisfaction, which is defined as the pleasure derived from being able to do your work well or to help others through your work. Compassion fatigue is used to measure the negative impact of caregiving on professionals, and this is further separated into two subsections, burnout and secondary traumatic stress (STS). Burnout is defined as feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. It can reflect the feeling that your efforts make no difference or can be associated with a very high workload or a non-supportive work environment. STS is work-related, secondary exposure to people who have experienced extremely or traumatically stressful events. The negative effects of STS can include fear sleep difficulties, intrusive images, or avoiding reminders of the person's traumatic experiences. For each of the three factors scores of 22 or less are considered low, 23 – 41 considered moderate and scores above 42 are considered high (Stamm, 2010).

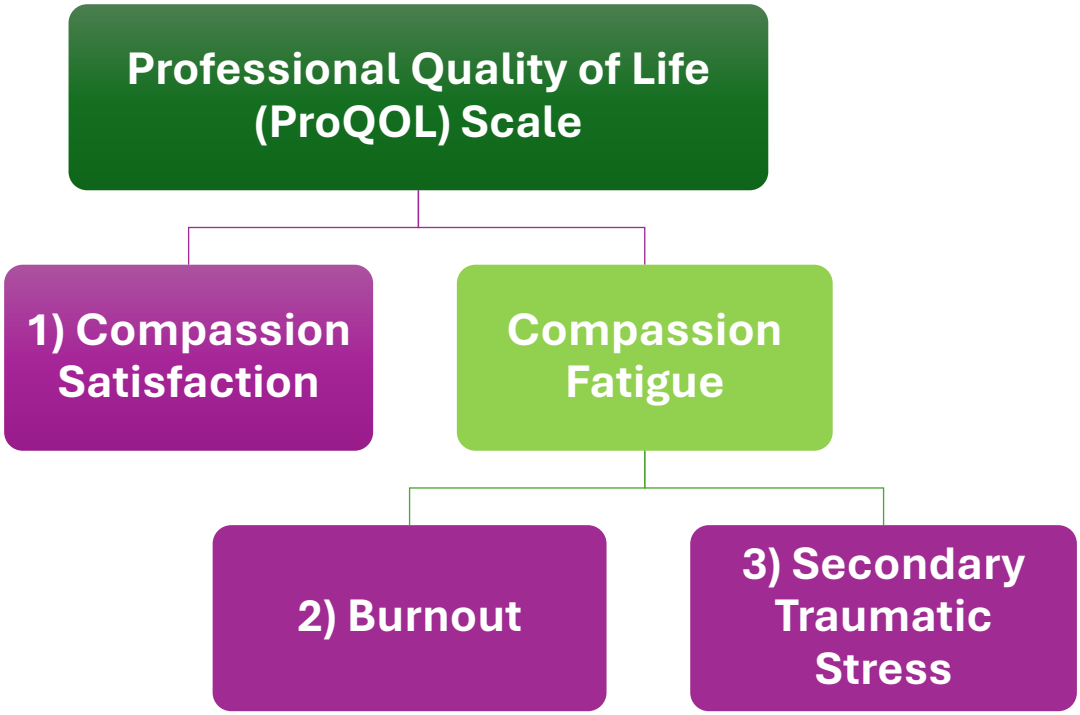


**Figure 5.1:** Three Factor Structure of The Professional Quality of Life Scale.

Stamm (2010) reported good internal consistency for the ProQOL-5 subscales, with Cronbach's alpha values of α = 0.88 for compassion satisfaction, α = 0.75 for burnout, and α = 0.81 for secondary traumatic stress. Similarly, Cieslak *et al.*, (2014), in a meta-analysis, found alpha values ranging from 0.65 to 0.83 for burnout and from 0.68 to 0.87 for secondary traumatic stress. In the current sample, the ProQOL-5 subscales demonstrated comparable internal consistency: α = 0.88 for compassion satisfaction, α = 0.76 for burnout, and α = 0.83 for secondary traumatic stress, indicating strong reliability within this population.

In terms of subscale interrelationships, Stamm (2010) found low shared variance between compassion satisfaction and secondary traumatic stress (STS) ($r$ = -0.14; 2%) and between compassion satisfaction and burnout ($r$ = −0.14; 2%), but a much higher correlation between burnout and STS ($r$ = 0.58; 34%). These finding are echoed in subsequent research suggesting a significant overlap between burnout and STS, particularly among professionals exposed to secondary trauma, supporting their conceptual link within the broader framework of compassion fatigue (Cieslak *et al.*, 2014).

While the ProQOL-5 is widely used and generally considered a reliable tool for assessing compassion fatigue and compassion satisfaction, some concerns remain about its psychometric properties, particularly its factor structure. There is ongoing debate as to whether the covariances among the 30 items are best explained by one, two, or three correlated factors (Hemsworth *et al.*, 2018; Geoffrion *et al.*, 2019). However, alternative factor models such as a bifactor model or a general professional quality of life factor (i.e., a continuum score) have yet to be tested or validated (Geoffrion *et al.*, 2019). As a result, this study retained the original three-factor structure to align with established scoring protocols (Stamm, 2010) and comparability with existing studies (Dodek *et al.*, 2016; Gonçalves *et al.*, 2024).

All other measurement tools identified and considered to measure professional quality of life outcomes in this study and the reasons for exclusion can be found in Appendix N.

## D. The Brief Resilient Coping Scale

The Brief Resilient Coping Scale (BRCS) is a brief scale that measures resilient coping, defined as the ability to quickly recover from adversity and stress. The focus is on adaptive responses to stress that reflect personal strength and the ability to recover quickly after setbacks (Sinclair and Wallston, 2004)[4]. The BRCS was selected for this study as the items measure many elements of resilience and coping that were identified as important by participants in the qualitative phase of this research such as a flexible and adaptive approach to problem-solving, emotional awareness and regulation and a positive coping mindset.

This tool is a four item, self-report measure, that uses a 5-point Likert scale ranging from '*1 = Does not describe me at all'* to '*5 = Describes me very well'*. The total sum score therefore can range from 4-20, and scoring categories are provided with scores between 4-13 indicating low resilient copers, scores between 14 – 16 indicating

[4] Permission was not required from the authors to use the BRCS in this research.

medium resilient copers and scores between 17 – 20 indicating high resilient copers (Sinclair and Wallston, 2004).

The Brief Resilient Coping Scale (BRCS) has demonstrated adequate psychometric properties as a brief outcome measurement tool across various populations. Numerous studies have confirmed the scale's unidimensional factor structure, validating its capacity to effectively measure resilient coping (Sinclair and Wallston, 2004; Kocalevent *et al.*, 2017; Mayordomo *et al.*, 2020; Albougami, 2024). Additionally, the BRCS has shown good construct validity, correlating positively with measures of personal coping resources and psychological well-being and negatively with psychosocial stress, loneliness, depressiveness and anxiety (Sinclair and Wallston, 2004; Mayordomo *et al.*, 2020; Petersen *et al.*, 2024). Recent research also supports its internal consistency, with Cronbach's alpha coefficients typically ranging from 0.76 to 0.78, indicating acceptable reliability (Petersen *et al.*, 2024). In the current sample, however, the Cronbach's alpha was slightly lower ($\alpha = 0.59$).

Other tools identified and considered to measure resilience and coping capacity in this study and the reasons for exclusion can be found in Appendix O.

## E. Helpful and Supportive Factors for working with MND

An open-ended question was used to identify factors perceived as helpful or supportive in sustaining their work in this area.

> *Is there anything that you find (or previously found) helpful/supportive for you as a healthcare professional when working with ALS/MND?*

See an overview of each of the survey sections and flow in Figure 5.2 below.

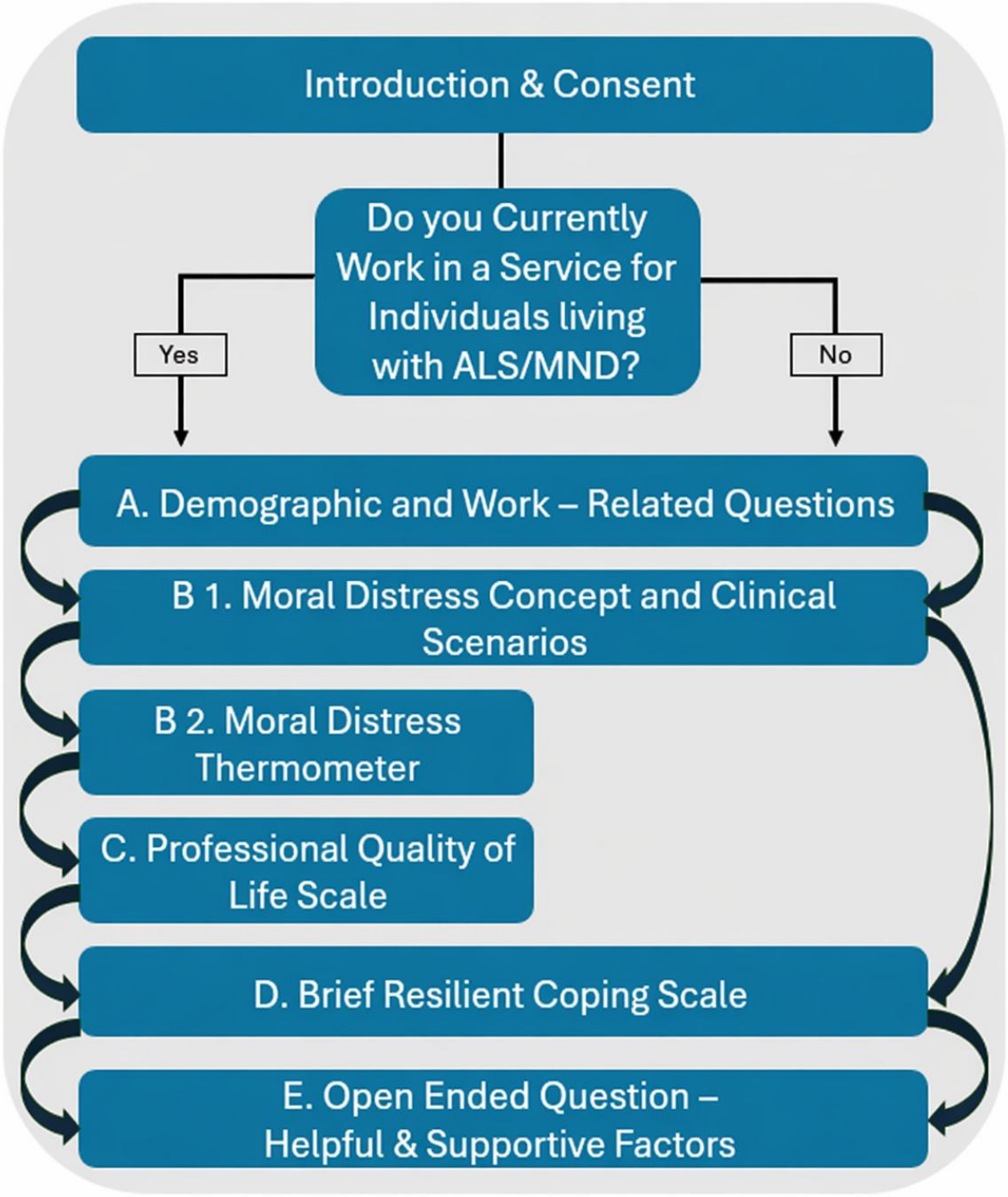


**Figure 5.2**: Survey Sections and Flow

### Ethical Approval

Ethical approval was obtained for this study from the School of Medicine, Research Ethics Committee in Trinity College Dublin on the 23.10.2024 (REAMS: 3500) (Appendix P).

### 5.2.4 Sampling and Recruitment

A number of MND organisations were approached for permission to distribute the survey information and link to HCPs on their mailing lists. Organisations were selected, for their direct access to professionals working within specialist MND services. Gatekeepers from the Motor Neurone Disease Association (MNDA UK) MND Professionals Community of Practice, TRICALS European Research Network and the International Alliance for ALS/MND Associations – European Members/EUpALS, distributed the study invitation, participant information leaflet and survey link to HCPs who met the study criteria on their mailing lists. They were briefed on the inclusion criteria (Table 5.2) and asked to distribute the survey specifically to those who met these criteria. They were also asked to share the survey with any HCPs who had recently left their service, within the previous 24 months, and may be interested in participating.

**Table 5.2:** Inclusion and Exclusion Criteria Communicated to Relevant Gatekeepers and Applied to Determine Respondent Eligibility for Data Analysis.

| **Inclusion and Exclusion Criteria** | |
|---|---|
| **Inclusion** | • Healthcare professionals working in MND care<br>• Healthcare professionals who are currently working with plwMND<br>• Healthcare professionals who have worked with plwMND in the past 24 months<br>• Healthcare professionals associated with one of the organisations selected for recruitment |
| **Exclusion** | • A respondent who is not a recognised healthcare professional or working with plwMND in a clinical role i.e. administration staff, research staff or volunteers<br>• A healthcare professional who has not worked with plwMND in the past 24 months<br>• Healthcare professionals who are not associated with the organisations who have been selected for recruitment |

### 5.2.5 Survey Distribution

The survey was distributed by the relevant gatekeepers (named above), via an anonymous web link between November 2024 and January 2025. Duplicate submissions were disabled by restricting multiple entries from the same device or IP

address, ensuring that each participant could only respond once. All responses were anonymous, and informed consent was obtained at the beginning of the survey.

### 5.2.6 Data Analysis

Quantitative data were analysed in R version 4.4.3 (R Core Team, 2024), using both descriptive and inferential statistics. Open-text responses were analysed in Microsoft Excel using a summative approach to content analysis (Hsieh and Shannon, 2005).

#### 5.2.6.1 Quantitative Analysis

##### Missing Data

Missingness maps were generated to visualise the extent and patten of missing data, and indicated that 2.2% of data were missing overall, representing a very small or '*negligible*' percentage (Mirzaei *et al.*, 2022). Survey drop-off was random and not associated with any demographic, work-related variable or survey question. The data were treated as missing completely at random (MCAR) and pairwise deletion or available case analysis was used during statistical analysis (Mirzaei *et al.*, 2022).

##### Distribution and Normality

Histograms were used to visually assess the distribution of data for the primary outcome measures, while the Shapiro–Wilk test was used to formally evaluate the data's fit to a normal distribution. The results indicated that scores on the ProQOL-5 burnout subscale followed a normal distribution ($p = 0.392$). However, all other outcome measures demonstrated significant deviations from normality: MD Thermometer ($p < 0.001$), ProQOL-5 secondary traumatic stress ($p = 0.004$), ProQOL-5 compassion satisfaction ($p = 0.047$), and Brief Resilient Coping Scale ($p < 0.001$).

## Statistical Analysis

### Descriptive Statistics

Descriptive statistics were calculated for demographic, work-related, and outcome measure variables. Continuous variables were summarised using means (M) and standard deviations (SD) for normally distributed data, and medians (Mdn) with interquartile ranges (IQR) for non-normally distributed data. Categorical variables were described using frequency counts and percentages.

### Bivariate Analysis

Chi-squared tests of independence ($\chi^2$) were performed to examine the associations between categorical demographic and work-related variables, where the expected cell frequency was sufficiently large (at least 5 in each cell). Pearson's correlation co-efficient ($r$) or Spearman's rank-order correlation ($r_s$) was used to assess the strength and direction of relationships between continuous variables, depending on the normality of the data. The magnitude of correlation co-efficient was interpreted using Cohens (1988) thresholds: $|r| \approx 0.1$ were considered small, $|r| \approx 0.3$ were considered medium and $|r| \approx 0.5$ large.

Bivariate analyses for non-normally distributed continuous variables (MD Thermometer, ProQOL-5 secondary traumatic stress and compassion satisfaction, and BRCS) were conducted using the non-parametric Kruskal-Wallis ($H$) and Mann-Whitney U tests ($U$). For the ProQOL-5 Burnout outcome, which met normality assumptions, the parametric equivalents, independent samples t-test ($t$) and one-way ANOVA ($F$), were used. Dunn's post-hoc test with Bonferroni correction was applied to identify significant pairwise differences following any significant Kruskal-Wallis' test results, while Tukey's Honestly Significant Difference (HSD) test was used for post-hoc comparisons after significant ANOVA findings. Variables demonstrating significant or near-significant associations were considered for inclusion in the multivariable models, alongside other model-building considerations, including multicollinearity and linearity.

### Multivariable Analysis

Multiple linear regression analyses were conducted to examine the independent effects of multiple predictors on MD intensity, Burnout, Secondary Traumatic Stress (STS), and Compassion Satisfaction (CS), while adjusting for potential confounding variables. Each model controlled for years of experience working with MND, gender, and profession. Log transformations were applied where necessary to satisfy the assumption of linearity. Assumptions of linearity, multicollinearity, homoscedasticity, and normality of residuals were assessed, with no violations detected in the final models. Linearity was evaluated through visual inspection of Q–Q plots, multicollinearity was assessed using Variance Inflation Factor (VIF) values, homoscedasticity was tested using the Breusch–Pagan test, and the Shapiro–Wilk test was used to assess the normality of residuals. To account for multiple comparisons in this exploratory analysis, Bonferroni-adjusted *p*-values and confidence intervals are reported, with significance determined at an alpha level of 0.05.

## 5.2.6.2 Content Analysis

Responses to open-text questions in sections A and E of the survey, as outlined above, were analysed using summative content analysis (Hsieh and Shannon, 2005). This analytic approach is commonly used for open ended survey questions, whereby keywords and categories are identified and quantified to determine the frequency of responses. The lead researcher read and re-read the open-text responses to identify keywords and categories from the data. A codebook was developed with codes inductively derived from the data. The responses were initially coded by the lead researcher and quantified using frequency counts. This approach was considered the most suitable as responses were in single word and short sentence formats. Individuals' responses could be coded and counted in multiple different categories. After the initial phase of coding and quantification, the codebook was reviewed and refined by the lead researcher to ensure that each category represented a unique and separate idea. The revised coding framework was then reviewed by the supervisory team. Discrepancies were discussed and resolved through consensus. Categories

were subsequently reported in order of frequency, accompanied by illustrative quotations from the responses. Frequency statistics reflect the number and percentage of respondents who mentioned each category.

#### Reporting

This study is reported in line with the Consensus-based Guideline for Reporting Survey Studies (CROSS) checklist (Sharma *et al.*, 2021)(Appendix Q).

## 5.3 Results

### Survey Responses

275 responses were recorded in total. 45 (16%) of the total were partially complete. Of the partially completed surveys 17 (6%) had >75% of the survey completed and were included in the final analysis, 28 (10%) had <30% completed and were excluded. A further 7 (2.5%) responses were excluded as they were not from HCP respondents (support staff, researcher).

Thus, 240 (87%) of the recorded surveys are included in the final analysis. 230 (96%) of these were from professionals currently working in a service for individuals living with MND, while 10 (4%) were no longer working in a service for individuals living with MND. As the sample size for those no longer working in an MND service was too small for statistical comparison, the data for both groups are presented separately below. The primary focus of this analysis is on those currently working in an MND service.

### 5.3.1 Participants

#### Not Currently Working with MND

The majority (*n* = 5/10, 50%) had last worked with MND in the previous 7-12 months, had been working part-time (*n* = 8 , 80%), were AHP's ( *n* = 9, 90%), in the 31–50 age category (*n* = 8, 80%), had 0-10 years of experience (*n* = 5, 50%), and were living in the UK (*n* = 5, 50%). There were no medics represented in this sample and no respondents under 30. The median percentage of their working week with plwMND was 28% (IQR:

9.5). A full breakdown of demographic and work-related data for those no longer working in a service for plwMND can be found in Appendix R.

Due to the small number of respondents in this category and only *n* = 1 (10%) indicating that they had left of changed their position because of factors related to working with MND, the remainder of the analysis in this chapter, focuses on the responses from the *n* = 230 participants who were currently working in an MND service.

### Currently Working with MND

Respondent currently working with MND reported spending a median of 41% of their working week working with MND patients. The majority were female *n* = 175/230 (76%), working full time *n* = 174 (76%), in the 31 – 50 age category *n* = 145 (63%), and had up to 10 years of experience working with MND *n* = 133 (58%). These respondents came from 17 European countries and from 11 different professional backgrounds (Table 5.3).

**Table 5.3:** Professions and Countries Represented for Respondents Currently Working in an MND Service

| Variable | N (%) |
|---|---|
| **Profession:** | |
| **Medics** | 70 (30.5) |
| **Nursing** | 46 (20) |
| Nurses | 41 (18) |
| Nursing Assistants | 5 (2) |
| **Allied Healthcare Professionals** | 114 (49.5) |
| Physiotherapists | 39 (17) |
| Occupational Therapists | 23 (10) |
| Speech and Language Therapists | 22 (9.5) |
| Psychologists | 14 (6) |
| Dietitians | 4 (2) |
| Social Workers | 4 (2) |
| MND care coordinators | 6 (2.5) |
| Psychomotor Therapists | 2 (1) |
| **Country:** | |
| United Kingdom | 63 (27) |
| France | 54 (23.5) |
| Republic of Ireland | 22 (9.5) |
| Denmark | 24 (10.5) |
| Sweden | 11 (5) |
| Netherlands | 8 (3.5) |
| Italy | 13 (5.5) |
| Belgium | 4 (1.7) |
| Czechia | 1 (0.4) |
| Germany | 4 (1.7) |
| Iceland | 9 (4) |
| Norway | 1 (0.4) |
| Poland | 4 (1.7) |
| Slovenia | 3 (1.3) |
| Spain | 5 (2) |
| Switzerland | 1 (0.4) |
| Turkey | 3 (1.3) |

## Demographic And Work-Related Differences Between Professional Groups

The respondents' professions were categorised into Medical ($n$ = 70), Nursing ($n$ = 46) and Allied Healthcare Professional (AHP) ($n$ = 114) groups, for the purpose of statistical analysis (Table 5.3).

Those categorised as medical were more likely to be male ($\chi^2$ =16.672, $p$ <0.001), working full-time ($\chi^2$ = 8.259, $p$ <0.05), in the 51+ age category ($\chi^2$ = 20.136, $p$ <0.001), and have 21+ years of experience ($\chi^2$ = 35.535, $p$ <0.001), compared to nurses or AHPs. Among nurses, a higher percentage of their working week was spent with MND patients (70%) compared to, AHPs (30%) or medics (40%) ($\chi^2$ = 19.906, $p$ <0.001). AHPs were more likely to be in the under 30 age category ($\chi^2$ = 20.136, $p$ <0.001), the 0-10 years of experience category ($\chi^2$ = 35.535, $p$ <0.001) and work part-time ($\chi^2$ = 8.259, $p$ <0.05), compared to medics and nurses. No other statistically significant differences were found in demographic or work-related variables across professional groups (Table 5.4).

**Table 5.4**: Demographic and Work-Related Data for Respondents Currently Working in an MND Service, Presented Overall and by Profession Group

| Variable | Overall (*n* = 230) | Medical (*n* = 70) | Nursing (*n* = 46) | AHP (*n* = 114) | p-value |
|---|---|---|---|---|---|
| | Mdn (IQR) | Mdn (IQR) | Mdn (IQR) | Mdn (IQR) | |
| Percentage of the working week spent with plwMND | 41 (60) | 41 (54) | **70 (50)** | 31(40) | <0.001 |
| | N (%) | N (%) | N (%) | N (%) | |
| **Working Pattern:** | | | | | |
| Full time | 174 (75.7) | **61 (87)** | 35 (76) | **78 (68.5)** | <0.05 |
| Part time | 56 (24.3) | **9 (13)** | 11 (24) | **36 (31.5)** | |
| **Gender:** | | | | | |
| Male | 53 (23) | **28 (40)** | 7 (15) | 18 (16) | <0.001 |
| Female | 175 (76) | **41 (58.5**) | 39 (85) | 95 (83) | |
| Non-Binary/third gender | 2 (1) | 1 (1.5) | 0 | 1 (1) | |
| **Age Category** | | | | | |
| Under 30 | 21 (9) | **0 (0)** | 4 (8.5) | **17 (15)** | <0.001 |
| 31-50 | 145 (63) | 43 (61.5) | 25 (54.5) | 77 (67.5) | |
| 51+ | 64(28) | **27 (38.5)** | 17 (37) | **20 (17.5)** | |
| **Years of Experience** | | | | | |
| 0-10 | 133 (58) | **21(30)** | 31(67) | **81(71)** | |
| 11-20 | 59 (26) | 26 (37) | 9 (19.5) | 24 (21) | <0.001 |
| 21+ | 38 (16) | **23 (33)** | 6 (13) | **9 (8)** | |
| **Currently Considering Leaving** | (*n* = 228) | | | | |
| Yes | 16 (7) | 3 (4) | 2 (4) | 11 (10) | - |
| No | 212 (93) | 67(96) | 44 (96) | 101 (90) | |
| **Considered Leaving in the Past** | (*n* = 212) | | | | |
| Yes | 42 (20) | 12 (18) | 10 (23) | 20 (20) | 0.824 |
| No | 170 (80) | 55 (82) | 34 (77) | 81 (80) | |
| **Period of Absenteeism** | (*n* = 226) | | | | |
| Yes | 28 (12.5) | 7 (10) | 7 (16) | 14 (12.5) | 0.646 |
| No | 198 (87.5) | 63 (90) | 37 (84) | 98 (87.5) | |
| **Intention to Work with MND in the Future** | (*n* = 226) | | | | |
| Yes | 213 (94) | 70 (100) | 40 (91) | 103 (92) | - |
| No | 13 (6) | 0 (0) | 4 (9) | 9 (8) | |
| **Heard of Moral Distress** | (*n* = 227) | | | | |
| Yes | 107 (47) | 35 (50) | 23 (52) | 49 (43) | |
| No | 120 (53) | 35 (50) | 21 (48) | 64 (56.6) | 0.511 |
| **Resonate with Moral Distress** | (*n* = 226) | | | | |
| Yes | 152 (67) | 39 (55) | 30 (70) | 83 (75.5) | |
| No | 46 (20.5) | 19 (27) | 10 (23) | 17 (15) | 0.101 |
| Not Sure | 28 (12.5) | 12 (17) | 3 (7) | 13 (11.5) | |

P-values from Kruskal-Wallis and Chi-square tests are presented to show differences between professional groups on each demographic and work-related variable. **Bold text** highlights categories with significantly higher or lower observed counts than expected. Mdn = median, IQR = interquartile range

### 5.3.2 Turnover Intention and Absenteeism

**Objective 1:** To determine rates of turnover intention and absenteeism, and to identify factors influencing these outcomes within this workforce.

## Turnover Intention

Two respondents (*n* = 2, 1%) reported that they had previously left their position due to factors related to working with MND but later returned after a short break. Among the remaining respondents (*n* = 228), 16 (7%) indicated that they were currently considering leaving or changing their position due to factors related to working with MND. Of those who were not currently considering leaving (*n* = 212), 42 (34%) reported that they had considered doing so in the past for similar reasons. In total, 60 respondents (26% of the overall sample) had left or considered leaving or changing their position, because of factors related to working with MND.

### Reasons for Considering Leaving or Changing Position

A total of 55 respondents provided reasons for why they had previously considered or were currently considering leaving or changing their positions within an MND service. The responses are categorised in Table 5.5.

**Table 5.5:** Reasons Influencing Intentions to Leave or Change Roles Within MND Services

1. **The Emotional Toll Experienced from Working with Cumulative Loss, Death, Grief and Suffering: (*n* = 29, 53%)**
   This related to the emotional and psychological strain on HCP's, experienced from working with emotionally challenging patient circumstances, witnessing suffering and cumulative patient losses, working with inevitable and repeated death and supporting family and informal caregivers with their own loss and grief.

   - *'The emotional toll of supporting people facing deterioration and death everyday'* (Psychologist)
   - '*Psychological burden related to the constant interaction with terminally ill patients'* (Medical)
   - *'Working with a patient population where everyone is dying is exhausting. It can be rewarding but you get tired'* (Speech and Language Therapist)
   - *'I find it difficult to repeatedly bear witness to peoples suffering'* (MND Care Coordinator)
   - *'Sadness of work and cumulative losses of patients and impact on staff'* (Psychologist)

2. **Psychological Strain Arising from Barriers to Providing Adequate Care (*n* = 16, 29%)**
   This related to reports of work-related stress, burnout, moral injury/distress, feelings of being overwhelmed or difficulties meeting the needs of MND patients/families due to work related demands or pressures.

   - '*Moral injury from not able to see patients quickly*' (Medical)
   - *'Distress at not being in a position to provide enough care/help/support'* (Nurse)
   - *'My mental health - The stress of being unable to provide a service in a timely fashion due to factors beyond my control'* (Occupational Therapist)

3. **The Demands of Managing an MND Caseload: (*n* = 16, 29%)**
   This related to the perceived demands of managing MND patient care and the associated workload, due to the complexity, frequency, intensity and time sensitive nature of the care that was often required to adequately meet and respond to their changing needs.

   - *'The workload associated with the role'* (Meidcal)
   - *'High caseload and high complexity'* (MND Care Coordinator)
   - *'Intrusive nature of the urgent work when trying to do other work/see other patients'* (Meidcal)
   - *'Volume of work'* (Psychologist)

4. **Feelings of Professional Futility or Helplessness: (*n* = 14, 25%)**
   This related to feelings of professional futility or helplessness that were predominantly but not exclusively reported by medical staff, experienced as a result of working with a terminal and progressive life altering condition, without being able to provide any disease modifying, life prolonging or reversible treatment options.

   - *'Lack of therapeutic satisfaction'* (Medical)
   - *'Lack of faith in helping the patient'* (Medical)
   - *'Difficulties in managing patients (i.e., lack of effective treatments and of diagnostic therapeutic plans)'* (Medical)
   - *'Emotional stress of not being able to offer effective therapy. The feeling of not being able to offer real help. Helplessness'* (Medical)

5. **Lack of MDT or Collegial Support: (*n* = 10, 18%)**
   This related to challenges reported within the respondent's MDT or a perceived lack of MDT collegial support making it difficult to provide the level of care required by patients/families living with MND.

   - *'Difficulties within team dynamics'* (Nurse)
   - *'Lack of support from colleagues in difficult cases with patients in crisis'* (Medical)
   - *'Demanding circumstances due to teamwork and difficult communications'* (Nurse)
   - *'Lack of MDT support'* (Medical)

6. **Organisational Factors/Resource Constraints: (*n* = 7, 13%)**
   This related to feelings of frustration or challenges in delivering adequate care for individuals/families living with MND due to health service or organisational level restrictions, or where the resources, processes or systems in place were perceived as misaligned with the needs of individuals/families living with MND.

   - '*Being unable to meet expectations of families due to NHS constraints'* (MND Care Coordinator)
   - '*Difficulty in providing material and human aid at home'* (Occupational Therapist)
   - '*Difficulty sourcing correct equipment in timely way'* (Occupational Therapist)
   - '*Frustration around the existing health and social care systems in place to support those living with MND'* (MND care coordinator)
   - *'Collapse of our hospital system which is no longer in line with the needs of our ALS patients*'. (Medical)

7. **Personal Reasons: (*n* = 1, 2%)**
   One respondent reported how their own personal circumstances and experience of personal bereavement made working with MND more challenging for them.

   - *'I have experienced several bereavements myself over the last two years'* (MND Care-Coordinator).

Responses provided by *n* = 55 respondents

Respondents were also asked what they considered doing instead if they were to leave their role working with MND. The most frequent response was to work with a different patient cohort (*n* = 32, 66%), of these 32 respondents, 11 (34%) reported that they would stay within the field of neurology but work with a different or more '*treatable*' neurological condition. The next most frequent responses were to change from healthcare/clinical work entirely (*n* = 5, 10%), work in research (*n* = 3, 6%) or work privately (*n* = 2, 4%).

## Absenteeism

A total of 12.5% of respondents (*n* = 28/228) reported taking a period of time off work during their career due to factors related to working with MND. The most frequently cited reasons were consistent with the findings related to turnover intentions (Table 5.5) and primarily reflected the personal emotional impact of working with patients and families affect by MND (*n* = 13, 45%), work-related stress or burnout (*n* = 9, 31%)

and feeling overwhelmed by caseload demands (*n* = 6, 21%). One respondent (*n* = 1, 3%) cited personal reasons. For most respondents, the duration of time off was measured in weeks (*n* = 10, 38%), followed by days (*n* = 4, 15%), a number of hours (*n* = 4, 15%), and, for a smaller proportion, months (*n* = 3, 12%). An additional two respondents indicated that, although they had not yet taken time off, they recognised a current need to do so. Another two respondents reported modifying their work schedules to manage the workload and emotional demands, such as '*working 70 % instead of 100% for 3 years*' and '*1 day a week I take off work with ALS patients'*.

### 5.3.3. Moral Distress

- **Objective 2**: To measure the occurrence of moral distress (MD) and clinical situations that may contribute to experiences of MD in MND care.
- **Objective 3:** To determine the level of MD experienced and the factors associated with its intensity.

#### Moral Distress – Occurrence

47% (*n* = 107/227) of total respondents reported having previously heard of the concept moral distress (MD) (Figure 5.3), while 67% (*n* = 152/226) indicated that the description of MD provided in the survey resonated with their experience of working with MND (Figure 5.4). While not statistically significant a higher percentage of AHP's (75%) and nurses (70%) felt that MD resonated with their experience of working with MND compared to medics (56%) (Figure 5.4).

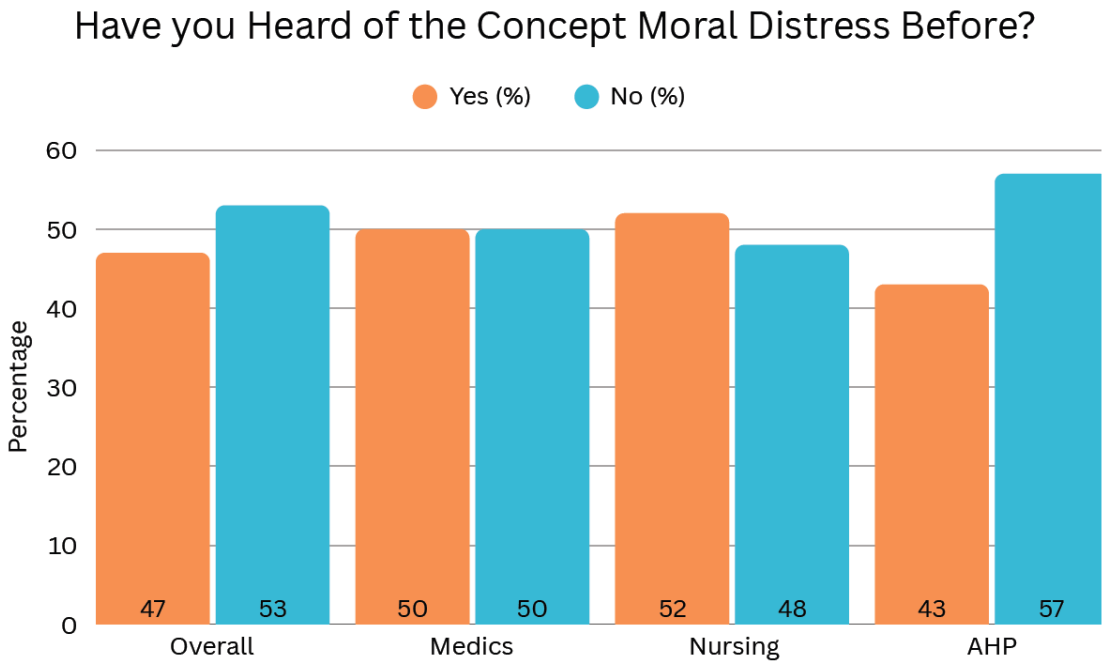


**Figure 5.3:** Bar Chart Representing the Percentage of Respondents Who Selected '*Yes*' or '*No*' to the Question '*Have You Heard of the Term Moral Distress Before*?', Overall and Within Each Professional Group.

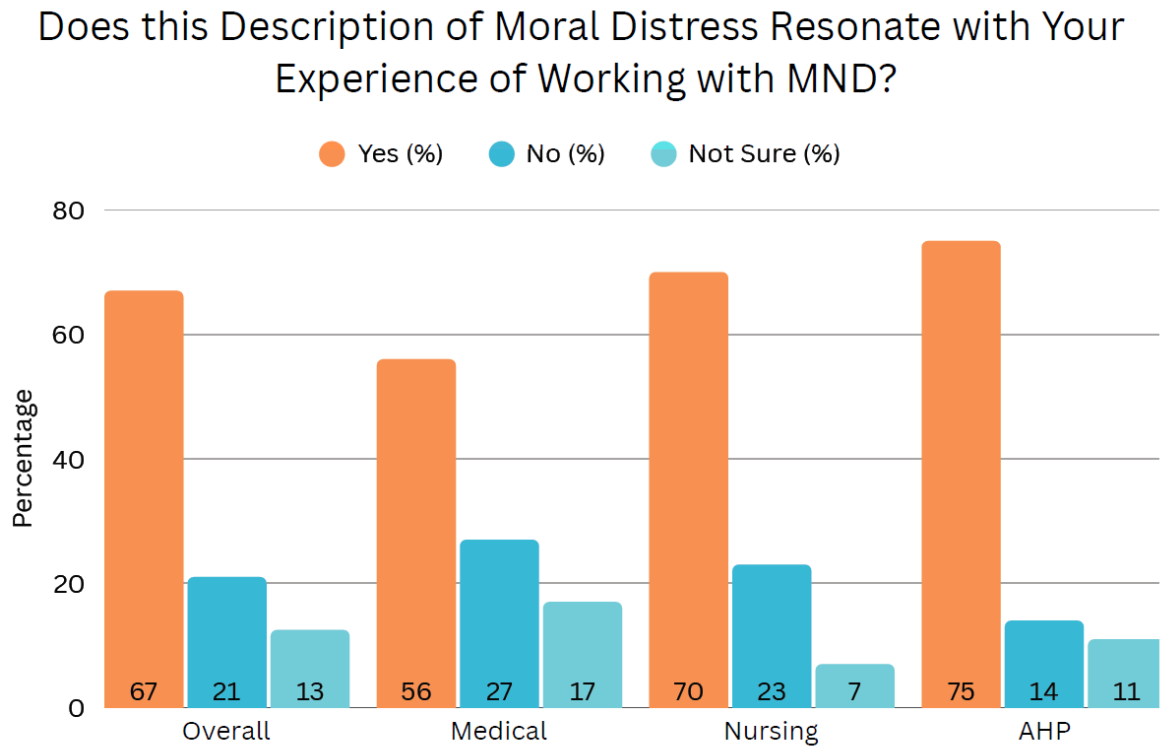


**Figure 5.4:** Bar Chart Representing the Percentage of Respondents Who Selected '*Yes*', '*No*' or '*Not Sure*' to the Question '*Does This Definition of Moral Distress Resonate with Your Experience of Working with MND*?', Overall and Within Each Professional Group.

**Table 5.6:** Potential Causes of Moral Distress for Healthcare Professionals Working in MND Care

| Number | Statement |
|---|---|
| **1.** | Feel unable to effectively plan for the future care of individuals with ALS/MND because of my uncertainty regarding the trajectory of disease progression. |
| **2.** | Feel pressure to provide care/intervention that I don't believe will benefit the individual with ALS/MND at the request of others, such as family, senior colleagues, or other services. |
| **3.** | Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. |
| **4.** | Feel that by initiating future care planning, I am adding to the individual's psychological distress. |
| **5.** | Feel unable to offer individuals with ALS/MND and their families the emotional support or comfort they need. |
| **6.** | Have difficulty communicating hope or optimism for individuals with ALS/MND with no available cure for the disease. |
| **7.** | Worry that the wishes of individuals with ALS/MND are not being respected when problems with their communication arise. |
| **8.** | Feel unable to provide an intervention that could benefit the individual with ALS/MND because of cognitive or behavioural changes. |
| **9.** | Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. |
| **10.** | Witness individuals with ALS/MND in distress or pain due to poorly managed symptoms. |
| **11.** | Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. |
| **12.** | Feel unable to effectively deliver care for an individual with ALS/MND due to a breakdown in the patient-clinician relationship. |
| **13.** | Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. |
| **14.** | Struggle to meet the needs of both individuals with ALS/MND and their family members because of their conflicting priorities or opinions. |
| **15.** | Have difficulty implementing care or interventions without family or informal caregiver support. |
| **16.** | Witness compromised care for individuals with ALS/MND because of poor communication between healthcare professionals. |
| **17.** | Witness care for individuals with ALS/MND being negatively affected because of staffing vacancies within a team or service. |
| **18.** | Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the person's care. |
| **19.** | Struggle to meet the needs/expectations of individuals with ALS/MND or their families due to limitations imposed by my organisation's policies or procedures. |
| **20.** | Witness individuals with ALS/MND struggling while waiting for necessary aids, devices, or services. |
| **21.** | Experience individuals with ALS/MND receiving unequal access to services/resources depending on the region where they live. |
| **22.** | Witness compromised care for individuals with ALS/MND due to lack of equipment/resources/bed capacity. |
| **23.** | Feel restricted to prioritise only certain aspects of care for individuals with ALS/MND due to limited time during appointments. |
| **24.** | Be required to care for more individuals with ALS/MND than I can safely care for. |

24 statements generated from analysis of the focus group data and identified as potential causes of moral distress for professionals working with MND. These statements were

included in the online survey to assess the most frequently encountered and distressing barriers to delivering optimal care for people and families living with MND. Statements 1–6 address clinical situations at the professional level; statements 7–12 at the patient or condition level; statements 13–15 at the family level; statements 16–18 at the team level; and statements 19–24 at the system or organisational level.

## Potential Contributors to Moral Distress Among Professionals Working in MND Care

Respondents were asked to select 'Yes' or 'No' to whether they had experienced each of 24 statements listed in Table 5.6 in their work with plwMND. Respondents gave a median of 14 '*yes*' responses (IQR = 7; possible range = 0–24). The 67% of respondents who identified with the experience of moral distress (MD) endorsed a greater number of these statements (Mdn: 16, $\chi^2$ = 33.737, $p$ <0.001) and reported higher intensities of MD on the MD Thermometer scale (Mdn: 4, $\chi^2$ = 33.722, $p$ <0.001), than those who did not resonate with MD or selected '*unsure*' (Table 5.7).

**Table 5.7:** Median MD Thermometer Scores and Number of Scenarios Endorsed, Stratified by Resonance with the MD Description (yes/no/not sure)

| **Response Category – Resonate with Moral Distress?** | **Yes** | **No** | **Not Sure** | **Chi-square ($\chi^2$) Test Results (p-value)** |
|---|---|---|---|---|
| **N (%)** | 128 (67%) | 46 (20.5%) | 28 (12.5%) | - |
| **Median MD Thermometer Score** | 4 (Uncomfortable) | 2 (Mild) | 2 (Mild) | $\chi^2$ = 33.737 $p$ <0.001 |
| **Median Number of Statements Selected "Yes"** | 16 | 10 | 10 | $\chi^2$ = 33.722 $p$ <0.001 |

## Most Frequently Experienced Clinical Situations Contributing to Moral Distress

The statement most frequently experienced was the same across all professional groups:

1. **'***Witness individuals with MND struggling while waiting for necessary aids, devices, or services'* (experienced by 89% of total respondents)

The second most frequently experienced statement was:

2. *'Experience individuals with MND receiving unequal access to services/resources depending on the region where they live'* (experienced by 77% of total respondents)

Followed by:

3. '*Witness individuals with MND in distress or pain due to poorly managed symptoms'* (experienced by 71%)
4. '*Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment*' (experienced by 71%)
5. '*Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services'* (experienced by 70%)

## Clinical Situations Contributing to Moral Distress Differences Across Professional Groups

The proportion of respondents who reported experiencing six of the 24 clinical statements differed significantly across professional groups (Statements 1, 3, 10, 14, 15, 16). There were no significant between-group differences across the remaining statements (Table 5.8).

**Table: 5.8:** Overall and Professional Group Endorsement of Statements Provided

| Statement | Overall (*n* = 220) | | Medical (*n* = 69) | | Nursing (*n* = 42) | | AHPs (*n* = 109) | | ***p*-value** |
|---|---|---|---|---|---|---|---|---|---|
| | **Yes N (%)** | **Rank** | **Yes N (%)** | **Rank** | **Yes N (%)** | **Rank** | **Yes N (%)** | **Rank** | |
| 1. Feel unable to effectively plan for the future care of individuals with MND because of my uncertainty regarding the trajectory of disease progression. | 113 (51) | **17** | 29 (42) | **20.5** | 17 (40) | **16.6** | 67 (61) | **8** | 0.011* |
| 2. Feel pressure to provide care/intervention that I don't believe will benefit the individual with MND at the request of others, such as family, senior colleagues, or other services. | 105 (47) | **19** | 33 (47) | **18** | 23 (45) | **14** | 53 (48) | **19.5** | 0.933 |
| 3. Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. | 71 (32) | **22** | 14 (20) | **24** | 13 (30) | **22** | 44 (40) | **22** | 0.019* |
| 4. Feel that by initiating future care planning, I am adding to the individual's psychological distress. | 113 (51) | **17.5** | 38 (55) | **13.5** | 16 (38) | **19** | 59 (54) | **16** | 0.159 |
| 5. Feel unable to offer individuals with MND and their families the emotional support or comfort they need. | 121 (55) | **15** | 35 (50) | **17** | 25 (59) | **6** | 61 (55) | **14.5** | 0.639 |
| 6. Have difficulty communicating hope or optimism for individuals with MND with no available cure for the disease. | 126 (57) | **13** | 38 (55) | **13.5** | 24 (57) | **8.5** | 64 (58) | **11** | 0.892 |
| 7. Worry that the wishes of individuals with MND are not being respected when problems with their communication arise. | 133 (60) | **7** | 38 (55) | **13.5** | 24 (57) | **8.5** | 71 (65) | **6** | 0.363 |
| 8. Feel unable to provide an intervention that could benefit the individual with MND because of cognitive or behavioural changes. | 129 (59) | **9.5** | 42 (60) | **11** | 24 (57) | **8.5** | 63 (57) | **12.5** | 0.899 |
| 9. Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. | 155 (71) | **3.5** | 47 (68) | **6.5** | 29 (69) | **5** | 79 (72) | **2.5** | 0.804 |
| 10. Witness individuals with MND in distress or pain due to poorly managed symptoms. | 155 (70) | **3.5** | 58 (84) | **3** | 23 (54) | **11.5** | 74 (67) | **5** | 0.003** |
| 11. Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. | 130 (59) | **8** | 46 (66) | **8.5** | 23 (54) | **11.5** | 61 (55) | **14.5** | 0.301 |
| 12. Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. | 154 (70) | **5** | 47 (68) | **6.5** | 32 (76) | **2.5** | 75 (68) | **4** | 0.619 |
| 13. Feel unable to effectively deliver care for an individual with MND due to a breakdown in the patient-clinician relationship. | 62 (28) | **24** | 26 (37) | **22** | 11 (26) | **23.5** | 25 (22) | **24** | 0.098 |

| Statement | Overall (*n* = 220) | | Medical (*n* = 69) | | Nursing (*n* = 42) | | AHPs (*n* = 109) | | *p*-value |
|---|---|---|---|---|---|---|---|---|---|
| | Yes N (%) | Rank | Yes N (%) | Rank | Yes N (%) | Rank | Yes N (%) | Rank | |
| 14. Struggle to meet the needs of both individuals with MND and their family members because of their conflicting priorities or opinions. | 129 (59) | **9.5** | 44 (63) | **10** | 16 (38) | **19** | 69 (63) | **7** | 0.011* |
| 15. Have difficulty implementing care or interventions without family or informal caregiver support. | 123 (56) | **14** | 48 (69) | **5** | 17 (40) | **16.5** | 58 (53) | **17** | 0.008** |
| 16. Witness compromised care for individuals with MND because of poor communication between healthcare professionals. | 127 (58) | **11.5** | 46 (66) | **8.5** | 18 (42) | **15** | 63 (57) | **12.5** | 0.048* |
| 17. Witness care for individuals with MND being negatively affected because of staffing vacancies within a team or service. | 127 (58) | **11.5** | 38 (55) | **13.5** | 24 (57) | **8.5** | 65 (59) | **10** | 0.832 |
| 18. Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the person's care. | 116 (53) | **16** | 37 (53) | **16** | 22 (52) | **13** | 57 (52) | **18** | 0.984 |
| 19. Struggle to meet the needs/expectations of individuals with MND or their families due to limitations imposed by my organisation's policies or procedures. | 99 (45) | **20** | 32 (46) | **19** | 14 (33) | **21** | 53 (48) | **19.5** | 0.230 |
| 20. Witness individuals with MND struggling while waiting for necessary aids, devices, or services. | 196 (89) | **1** | 65 (94) | **1** | 38 (90) | **1** | 93 (85) | **1** | 0.171 |
| 21. Experience individuals with MND receiving unequal access to services/resources depending on the region where they live. | 170 (77) | **2** | 59 (85) | **2** | 32 (76) | **2.5** | 79 (72) | **2.5** | 0.128 |
| 22. Witness compromised care for individuals with MND due to lack of equipment/resources/bed capacity. | 150 (68) | **6** | 53 (76) | **4** | 31 (73) | **4** | 66 (60) | 9 | 0.052 |
| 23. Feel restricted to prioritise only certain aspects of care for individuals with MND due to limited time during appointments. | 92 (42) | **21** | 29 (42) | **20.5** | 16 (38) | **19** | 47 (43) | **21** | 0.854 |
| 24. Be required to care for more individuals with MND than I can safely care for. | 67 (30) | **23** | 23 (33) | **23** | 11 (26) | **23.5** | 33 (30) | **23** | 0.729 |

The table shows the number and percentage of respondents, overall and by professional group, who selected '*yes*' to experiencing each clinical scenario in their work with plwMND, along with the rank order of the most frequently endorsed scenarios in each group. Chi-squared tests were used to determine differences in responses between groups, with corresponding *p*-values reported. Blue shading indicates lower-than-expected frequencies; orange shading indicates higher-than-expected frequencies. **<0.05, **<0.01, ***<0.001*.

### Situations Contributing to Moral Distress Rated as Most Distressing

Respondents who selected *'yes'* to experiencing any of the 24 clinical scenarios were subsequently asked to identify the five they found most distressing when working with plwMND. The top five indicated by each professional group are presented in Table 5.9. The overall results can be found in Appendix S. Notably, every statement was selected by at least one respondent as among their top five most distressing situations, highlighting the broad range of challenges experienced. When viewed through the multilevel framework, the highest-rated stressors across professional groups reflected a combination of service or organisational factors, complexities associated with the patient's condition, and family-level challenges, indicating that MD is likely arising from barriers operating at multiple levels.

**Table 5.9:** The Top Five Most Distressing Scenarios Ranked by Each of The Professional Groups

| |
|---|
| **Medical Top 5:**<br>• Witness individuals with MND struggling while waiting for necessary aids, devices, or services.<br>• Experience individuals with MND receiving unequal access to services/resources depending on the region where they live.<br>• Witness compromised care for individuals with MND due to lack of equipment/resources/bed capacity.<br>• Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services.<br>• Witness individuals with MND in distress or pain due to poorly managed symptoms. |
| **Nursing Top 5:**<br>• Witness compromised care for individuals with MND due to lack of equipment/resources/bed capacity.<br>• Experience individuals with MND receiving unequal access to services/resources depending on the region where they live.<br>• Witness individuals with MND struggling while waiting for necessary aids, devices, or services.<br>• Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services.<br>• Feel unable to offer individuals with MND and their families the emotional support or comfort they need. |
| **AHPs Top 5:**<br>• Witness individuals with MND struggling while waiting for necessary aids, devices, or services.<br>• Worry that the wishes of individuals with MND are not being respected when problems with their communication arise.<br>• Have difficulty communicating hope or optimism for individuals with MND with no available cure for the disease.<br>• Feel unable to provide an intervention that could benefit the individual with MND because of cognitive or behavioural changes.<br>• Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services |

### The Moral Distress Thermometer: The Intensity of Moral Distress Experienced by Professionals Working in MND Care

The overall median MD Thermometer score was 3 (IQR = 3). In terms of MD experienced over the previous two weeks, most respondents reported levels described as either *mild* (21%) or *uncomfortable* (18%). However, one-quarter (25%) reported levels of distress rated as *distressing* or higher, with 6% selecting *intense*. Only 10% of respondents indicated experiencing no MD in the previous two weeks (Figure 5.5).

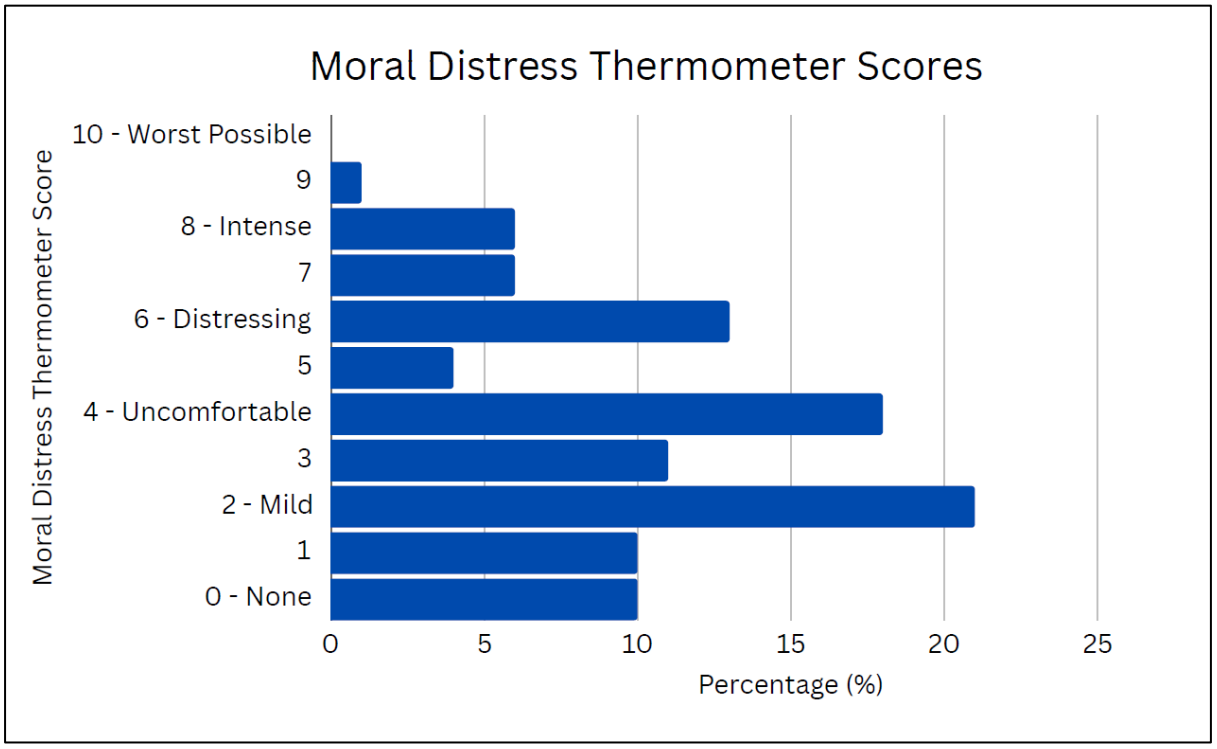


**Figure 5.5:** The Intensity of Moral Distress Reported by All Respondents on the MD Thermometer Scale

### Moral Distress Thermometer Bivariate Analysis

Bivariate analysis suggested that female respondents experienced higher intensities of moral distress (MD), than males ($U$ = 5096.5, $p$ = 0.032). Higher intensities of MD were also observed with a higher percentage of the working week spent with MND patients ($r_s$ = 0.254, $p$ = 0.0001), a current or past intention to leave or change positions ($U$ = 208, $p$ = 0.002) and higher levels of burnout ($r_s$ = 0.470, $p$ <0.001) and secondary traumatic stress ($r^2$ = 0.525, p <0.001). While lower intensities of MD were weakly associated with higher levels of resilient coping ($r_s$ = -0.137, $p$ = 0.045) and compassion satisfaction ($r_s$ = -0.248, $p$ <0.001). There were no differences observed between professional groups, age or experience categories, work patterns or work settings (Table 5.10).

### Moral Distress Thermometer Multivariable Analysis

After adjusting for professional and work-related variables, multiple linear regression analysis indicated that only burnout ($\beta$ = 0.106, $p$ <0.05) and secondary traumatic stress ($\beta$ = 2.881, $p$ <0.001) remained significant, independent predictors of the intensity of MD reported on the MD thermometer. No other variables in the model reached statistical significance (Table 5.10). This model explained 34% of the variance in MD Thermometer scores (Adjusted $R^2$ = 0.34).

### Moral Distress and Intention to Leave

100% of respondents who were considering leaving or changing their position due to factors related to working with MND indicated that the description of MD resonated with their experience of working with this population (15/15; $\chi^2$ = 7.77, $p$ = 0.020). 88% of those who had previously considered leaving their position for similar reasons also resonated with experiencing MD in their work with plwMND (36/41; $\chi^2$ = 13.19, $p$ = 0.001).

**Table 5.10:** MD Thermometer Scores: Bivariate and Multivariable Analysis

| **Moral Distress Thermometer** | | |
|---|---|---|
| **Variable** | **Bivariate Analysis[1]**<br>**Test stat (*H,U,* $r_s$), *p*-value** | **Multivariable Analysis[2]**<br>***β* [95%CI]** |
| **Profession Group** | *H* = 0.694, *p* = 0.707 | |
| **AHP (ref)** | | ~ |
| **Medical** | | 0.192 [-0.788, 1.174] |
| **Nursing** | | 0.861 [-0.260, 1.983] |
| **Gender** | *U* = 5096.5, *p* = 0.032* | |
| **Female (ref)** | | ~ |
| **Male** | | -0.298 [-1.257,0.662] |
| **Experience** | *H* = 1.273, *p* = 0.529 | |
| **0-10 (ref)** | | ~ |
| **11-20** | | 0.133 [-0.832, 1.098] |
| **21+** | | -0.428 [-1.594, 0.737] |
| **Percentage of work week with MND** | $r_s$ = 0.254, *p* = 0.0001*** | 0.008 [-0.005, 0.022] |
| **Work Setting** | | |
| **Inpatient** | *U* = 499, *p* = 0.065 | |
| **No (ref)** | | ~ |
| **Yes** | | 0.673 [-0.129, 1.474] |
| **Outpatient** | *U* = 590, *p* = 0.471 | - |
| **Community** | *U* = 5179.5, *p* = 0.929 | - |
| **Turnover Intention** | *U* = 209, *p* = 0.002*** | 0.441 [-0.522, 1.403] |
| **Absenteeism** | *U* = 208, *p* = 0.072 | -0.389 [-1.639, 0.862] |
| **Burnout** | $r_s$ = 0.470, *p* <0.001*** | **0.106 [0.002, 0.210] *** |
| **Secondary Traumatic Stress $^{log}$** | $r_s$ = 0.525, *p* <0.001*** | **2.881 [0.863, 4.899] ***** |
| **Coping Resilience** | $r_s$ = -0.137, *p* = 0.045* | 0.008 [-0.172, 0.189] |
| **Age** | *H* = 3.674, *p* = 0.159 | - |
| **Work Pattern (Part time/Full time)** | *U* = 4286.5, *p* = 0.723 | - |
| **Compassion Satisfaction** | $r_s$ = -0.248, *p* <0.001*** | - |

[1]Bivariate non-parametric analyses were conducted to examine between-group differences in MD Thermometer scores, with statistical significance determined at α = 0.05.

[2]Multivariable linear regression was used to further assess the impact of key variables on the primary outcome (total MD Thermometer score), adjusting for the effects of all other included predictors. Bonferroni-adjusted confidence intervals and *p*-values are reported to control for multiple comparisons. Statistical significance is indicated as follows*: *<0.05, **<0.01, ***<0.001*.

### 5.3.4 Professional Quality of Life

- **Objective 4**: To measure the Professional Quality of Life of healthcare professionals working with MND using the constructs of burnout, compassion fatigue and compassion satisfaction.
- **Objective 5**: To examine the relationships between professional well-being and QOL measures, demographic characteristics, and work-related factors, to identify risk and protective factors associated with the well-being of healthcare professionals in MND care.

**Table 5.11:** Subscale scores for the Professional Quality of Life Scale (ProQOL-5) and Brief Resilient Coping Scale (BRCS)

| **ProQOL-5 Sub-Scales** (*n* = 217) | **Low (≤ 22)** n (%) | **Moderate (23 – 41)** n (%) | **High (≥ 42)** n (%) |
|---|---|---|---|
| Burnout | 113 (52) | 104 (48) | 0 (0) |
| Secondary Traumatic Stress | 141 (65) | 75 (34.5) | 1 (0.5) |
| Compassion Satisfaction | 0 (0) | 143(66) | 74 (34) |
| **Brief Resilient Coping Scale** (*n* = 215) | **Low Resilient Copers (4-13)** | **Medium Resilient Copers (14 -16)** | **High Resilient Copers (17- 20)** |
| | 58 (27) | 125 (58) | 32 (15) |

ProQOL subscale scores are classified according to established cut-off ranges, with respondents grouped into low, moderate, or high categories (Stamm, 2010). Scores from the BRCS are categorised according to established thresholds, grouping respondents into low, medium, or high resilient coping levels (Sinclair and Wallston, 2004).

A correlation matrix presenting pairwise Spearman rank-order correlation coefficients between MD Thermometer total scores, ProQOL-5 subscale scores, and BRCS total scores is presented in Appendix T.

#### Subgroup Analysis of The Allied Healthcare Professional Group Professional Quality of Life Scores

A sub-group analysis of allied healthcare professional (AHP) groups to determine between group differences on professional well-being and quality of life outcomes.

Four professional groups (Occupational Therapy, Physiotherapy, Psychology, and Speech and Language Therapy), with the greatest response rates, were compared across measures of moral distress, Professional Quality of Life (ProQOL – v5) (Burnout, Secondary Traumatic Stress, Compassion Satisfaction) and Resilient Coping (BRCS) using Kruskal–Wallis tests. None of the Kruskal–Wallis tests were statistically significant, indicating no evidence of differences between the professional groups on any of the outcome measures. See full details of the analysis completed in Appendix U.

## The Negative Impact of Working in MND Care on Professional Quality of Life

### 5.3.4.1 Burnout

The mean burnout score, measured using the ProQOL-5 subscale, was 23 (SD: 5.4). As per ProQOL-5 normative cut off scores, this indicates moderate burnout. No respondents were identified as having scores ≥42, indicative of high burnout. The majority *n* = 113 (52%) were in the low burnout range, while *n* = 104 (48%) fell within the moderate burnout range (Table 5.11) (Stamm, 2010).

#### Burnout Bivariate Analysis

There was a significant difference in burnout scores between professional groups ($F = 6.000$, $p = 0.003$). Tukey HSD post hoc tests indicated that nurses had significantly lower burnout scores than AHPs (mean difference = −2.93, 95% CI [−5.25, −0.60], $p = 0.009$) and medics (mean difference = −3.52, 95% CI [−6.01, −1.02], $p = 0.003$). There was no significant difference between medics and AHPs (mean difference = 0.59, 95% CI [−1.35, 2.53], p = 0.75). Those with a current or past intention to leave or change position ($t = -4.579$, $p < 0.001$) and those who resonated with the experience of moral distress (MD) ($F = 11.42$, $p < 0.001$), experienced higher levels of burnout. There was a weak association between burnout and the percentage of the working week with spent with MND patients ($r = 0.137$, $p = 0.044$). While stronger associations

were observed between burnout and the intensity of MD reported on the MD thermometer ($r$ = 0.469, $p$ <0.001) and STS scores ($r$ = -0.625, $p$ < 0.001). Higher resilient coping ($r$ = -0.308, $p$ <0.001) and compassion satisfaction scores ($r$ = 0.686, $p$ <0.001) were associated with reduced burnout. There were no differences observed for gender, age, experience, work pattern, work setting or absenteeism (Table 5.12).

### Burnout Multivariable Analysis

In the multivariable analysis, after controlling for professional and work-related variables, higher moral distress intensity ($\beta$ = 0.590, $p$ <0.001) and having more than 21 years of experience working with MND ($\beta$ = 2.650, $p$ <0.01) were independently associated with higher levels of burnout. While being in the nursing profession ($\beta$ = -2.490, $p$ <0.01) and reporting higher levels of compassion satisfaction ($\beta$ = –0.438, $p$ <0.001) were both protective factors associated with lower levels of burnout (Table 5.12). This model explained 53% of the variance in burnout scores (Adjusted $R^2$ = 0.53).

**Table 5.12**: Burnout: Bivariate and Multivariable Analyses

| | **Burnout** | |
|---|---|---|
| **Variable** | **Bivariate Analysis[1] Test statistic (*F,t r*), *p*-value** | **Multivariable Analysis[2] *β* [95%CI]** |
| **Profession Group** | *F* = 6.000, *p* = 0.003** | † |
| AHP (ref) | | |
| Medical | | -0.029 [-1.953, 1.895] |
| Nursing | | **-2.490 [-4.609, -0.371] ** ** |
| **Gender** | *t* = 1.53, *p* = 0.13 | |
| Female (ref) | | ~ |
| Male | | -0.450 [-2.315, 1.414] |
| **Experience** | *F* = 0.967, *p* = 0.382 | † |
| 0-10 (ref) | | |
| 11-20 | | 0.232 [-1.630, 2.096] |
| 21+ | | **2.650 [0.382, 4.918] ** ** |
| **Percentage of work week with MND** | *r* = 0.137, *p* = 0.044* | 0.004 [-0.022, 1.414] |
| **MD Thermometer** | *r* = 0.469, *p* <0.001*** | **0.590 [0.211, 0.969] *** ** |
| **Resonate with MD** | *F* = 11.42, *p* <0.001*** | |
| No (ref) | | ~ |
| Yes | | 1.420 [-0.757, 3.598] |
| Not Sure | | 0.891 [-1.889, 3.673] |
| **Compassion Satisfaction** | *r* = 0.686, *p* <0.001*** | **-0.438 [-0.598, -0.279] *** ** |
| **Coping Resilience** | *r* = -0.308, *p* <0.001*** | -0.220 [-0.587, 0.142] |
| **BRCS Emotional Control** | *r* = -0.313, *p* <0.001*** | |
| **BRCS Growth** | *r* = *-0.389*, *p* <0.001*** | |
| **BRCS Creativity** | *r* = *-0.270, p* <0.001*** | |
| **BRCS Adaptation** | *r* = - 0.002*, p* = 0.982 | |
| **Turnover Intention** | *t* = -4.579, *p* <0.001*** | |
| No (ref) | | |
| Yes | | 1.220 [-0.662, 3.103] |
| **Absenteeism** | *t* = -2.01, *p* = 0.053 | |
| No (ref) | | ~ |
| Yes | | 1.767 [-0.587, 4.121] |
| **Secondary Traumatic Stress** | *r* = -0.625, *p* <0.001*** | - |
| **Age** | *F* = 0.157, *p* = 0.855 | - |
| **Work Pattern (Part time/Full time)** | *t* = -0.681, *p* = 0.498 | - |
| **Work Setting** | | - |
| Inpatient: | *t* = 0.479, *p* = 0.632 | |
| Outpatient: | *t* = -0.837, *p* = 0.404 | |
| Community: | *t* = -0.056, *p* = 0.955 | |

[1]Bivariate, parametric analyses were conducted to examine between-group differences and associations between variables and the burnout subscale of the ProQOL-5, with statistical significance determined at α = 0.05. [2]Multivariable linear regression was used to further assess the impact of key variables on burnout scores, adjusting for the effects of all other included predictors. Bonferroni-adjusted confidence intervals and p-values are reported to

control for multiple comparisons. Type 3 *p*-values are denoted with † if they are below 0.05. Statistical significance is indicated as follows: **<0.05, **<0.01, ***<0.001*.

### 5.3.4.2 Secondary Traumatic Stress

The median secondary traumatic stress (STS) score measured using the ProQOL-5 was 20.89 (IQR 5.9). As per the ProQOL-5 normative data, this represents low median levels of STS in this sample. Only one respondent had a score ≥42, meeting the criteria for high STS, the majority *n* = 141 (65%) were identified as falling in the low range, while *n* = 75 (34.5%) met the criteria for moderate STS (Stamm, 2010) (Table 5.11).

#### Secondary Traumatic Stress Bivariate Analysis

Bivariate analyses indicated a significant difference in secondary traumatic stress (STS) scores between professional groups ($H$ = 6.196, $p$ = 0.045). Dunn's post hoc tests showed that nurses experienced significantly lower STS scores than allied health professionals ($Z$ = 2.49, adjusted $p$ = 0.038). Those with a current or past intention to leave or change positions ($U$ = 258, $p$ <0.001), those who had a period of absenteeism ($U$ = 131, $p$ <0.001), and those who resonated with the experience of MD ($H$ =24.143, $p$ <0.001) all reported higher levels of STS. Additionally, higher levels of STS were strongly associated with greater intensity of MD as measured by the MD Thermometer ($r_s$ = 0.525, $p$ <0.001), increased burnout ($r$ = 0.686, $p$ <0.001), and weakly associated with a greater proportion of the work week spent with MND patients ($r_s$ = 0.210, $p$ = 0.001). Higher levels of compassion satisfaction ($r_s$ = -0.272, $p$ <0.001) and resilient coping ($r_s$ = -0.194, $p$ <0.001) were also weakly associated with lower STS. There were no significant differences for experience, age, work setting or work pattern (Table 5.13).

#### Secondary Traumatic Stress Multivariable Analysis

Multivariable analysis revealed that higher moral distress intensity ($\beta$ = 0.040, $p$ <0.001) and having taken a period of work absence ($\beta$ = 0.197, $p$ <0.001) were independent predictors of higher STS. While being in the nursing profession ($\beta$ = –0.157, $p$ <0.01) and reporting greater perceived emotional control on the BRCS item,

"*Regardless of what happens to me, I believe I can control my reaction to it*" ($\beta$ = –0.063, $p$ <0.05) were protective factors associated with lower STS levels (Table 5.13). This model explained 43% of the variance in STS scores (Adjusted $R^2$ = 0.43).

**Table 5.13**: Secondary Traumatic Stress: Bivariate and Multivariable Analyses

| Secondary Traumatic Stress | | |
|---|---|---|
| **Variable** | **Bivariate Analysis[1]**<br>**Test stat (*H, U, $r_s$*), *p*-value** | **Multivariable Analysis[2]**<br>***β* [95%CI]** |
| **Profession Group** | *H* = 6.196, *p* =0.045* | † |
| AHP (ref) | | ~ |
| Medical | | 0.001 [-0.119, 0.100] |
| Nursing | | **-0.157 [-0.278, -0.037] ** ** |
| **Gender** | *U* = 5215.5, *p* = 0.012* | |
| Female (ref) | | ~ |
| Male | | 0.025 [-0.131, 0.081] |
| **Experience** | *H* = 0.466, *p* = 0.792 | |
| 0-10 (ref) | | ~ |
| 11-20 | | -0.065 [-0.170, 0.041] |
| 21+ | | 0.029 [-0.010, 0.157] |
| **Percentage of work week with MND** | $r_s$ = 0.210, *p* = 0.001** | 0.001 [-0.001, 0.002] |
| **MD Thermometer** | $r_s$ = 0.525 *p* <0.001*** | **0.040 [0.019, 0.062] *** ** |
| **Resonate with MD** | *H* = 24.143, *p* <0.001*** | |
| No (ref) | | ~ |
| Yes | | 0.075 [-0.049, 0.198] |
| Not Sure | | 0.063 [-0.095, 0.220] |
| **Compassion Satisfaction** | $r_s$ = -0.272, *p* <0.001*** | -0.004 [-0.013, 0.004] |
| **Coping Resilience** | $r_s$ = -0.194, *p* <0.001*** | - |
| **BRCS Emotional Control** | $r_s$ = -0.271, *p* <0.001*** | **-0.063 [-0.118, -0.008] ** |
| **BRCS Growth** | $r_s$ = -0.233, *p* = 0.001 *** | |
| **BRCS Creativity** | $r_s$ = -0.145, *p* = 0.033 * | |
| **BRCS Adaptation** | $r_s$ = 0.017, *p* = 0.799 | |
| **Turnover Intention** | *U* = 258, *p* <0.001*** | |
| No | | ~ |
| Yes | | 0.075 [-0.021, 0.192] |
| **Absenteeism** | *U* = 131, *p* <0.001*** | |
| No (ref) | | ~ |
| Yes | | **0.197 [0.070, 0.338] *** ** |
| **Burnout** | *r* = 0.686, *p* <0.001*** | - |
| **Age** | *H* = 3.640, *p* = 0.162 | - |
| **Work Setting** | | - |
| Inpatient: | *U* = 604, *p* = 0.575 | |
| Outpatient: | *U* = 564, *p* = 0.814 | |
| Community: | *U* = 518, *p* = 0.938 | |
| **Work Pattern** (Part time/Full time) | *U* = 428, *p* = 0.877 | - |

[1]Bivariate, non-parametric analyses (Man Whitney-U test, Kruskal Wallis test and Spearman's rank order correlation) were conducted to examine between-group differences and associations between independent variables and the STS subscale of the ProQOL-5.
[2]Multivariable linear regression was used to further assess the impact of key variables on STS scores, adjusting for the effects of all other included predictors. Bonferroni-adjusted confidence intervals and *p*-values are reported to control for multiple comparisons. Type 3 *p*-values are denoted with † if they are below 0.05. Statistical significance is determined at α = 0.05 and is indicated as follows*: *<0.05, **<0.01, ***<0.001*.

### Reasons Provided for Not Continuing to Work in MND Care in the Future

For the small proportion of respondents (*n* = 13, 6%) who answered "*No"* to the question, "*Do you see yourself continuing to work with MND in the future?*", their open-text responses highlight reasons that align closely with the two professional quality of life factors measured above. Specifically, they emphasise the significant personal emotional toll of witnessing patient and family suffering, as well as experiences of and concerns relating to burnout (Table 5.14).

**Table 5.14:** Reasons Provided for Not Continuing to Work with MND in The Future

| Personal Emotional Toll | Burnout |
|---|---|
| *'I am not sure it is healthy emotionally to stay in this job for a full career as a psychologist. It requires a huge amount of my own emotional availability to be able to be present for the losses that individuals are experiencing, and I worry about burnout'* (Psychologist)<br><br>*'Sometimes what we see and hear we carry home with us and it's hard to shift. I think over time it just takes its toll, and there's other neuro physio jobs which would come with feeling like you've made more of a difference and without so much emotional cost'* (Physiotherapist) | *'I think at some point in the future I will need to leave before I burn out'* (MND Care Coordinator)<br><br>*'Because of the potential to become burnt out'* (Nurse)<br><br>'*I feel a little burnt out with it and working with other long term neuro conditions'* (Physiotherapist) |

Open-text responses were provided by *n* = 11 participants, detailing the reasons why they felt they would not continue to work in MND care in the future. These responses were categorised into two categories and are outlined in the table above, with examples.

## The Positive Impact of Working with MND on Professional Quality of Life

### 5.3.4.3 Compassion Satisfaction

High levels of compassion satisfaction (CS) were found for all professional groups. The overall median score for CS was 38.86 (IQR: 5.6), as per the ProQOL-5 normative data, this represents high median levels of CS in this sample. No respondents were identified as having low CS scores, the majority fell within the moderate range $n$ = 143 (66%), and $n$ = 74 (34%) were identified as having high levels of CS (Table 5.11).

#### Compassion Satisfaction Bivariate Analysis

Following a significant Kruskal–Wallis test, Dunn's post hoc analyses indicated that participants aged under 30 had significantly lower compassion satisfaction (CS) scores than those aged 31–50 ($Z$ = 2.51, adjusted $p$ = 0.037) and those aged 51 years and over ($Z$ = 3.14, adjusted $p$ = 0.005). Those who resonated with MD ($H$ = 6.584, $p$ = 0.040) and those reporting higher intensities of MD experienced lower levels of CS ($r_s$ = -0.248, $p$ = 0.0002). Those with a current or previous intention to leave or change position experienced lower CS ($U$ = 5592, $p$ = 0.005). CS was also strongly negatively associated with burnout ($r$ = -0.686, $p$ <0.001), weakly associated with STS ($r_s$ = -0.272 $p$ <0.001) and moderately positively associated with resilient coping ($r_s$ = 0.366, $p$ <0.001) (Table 5.15). There were no significant differences for profession group, gender, experience, absenteeism, work setting or work pattern.

#### Compassion Satisfaction Multivariable Analysis

After controlling for professional and work-related variables, multivariable analysis revealed that higher burnout levels were independently associated with lower compassion satisfaction (CS) ($\beta$ = –0.566, $p$ <0.001). Conversely, higher scores on the BRCS growth item, *"I believe I can grow in positive ways by dealing with difficult situations,"* were independently associated with higher CS ($\beta$ = 2.183, $p$ <0.001) (Table 5.15). This model explained 48% of the variance in CS scores (Adjusted $R^2$ = 0.48).

**Table 5.15:** Compassion Satisfaction: Bivariate and Multivariable Analyses

| **Compassion Satisfaction** | | |
|---|---|---|
| **Variable** | **Bivariate Analysis[1] Test stat (*H, U, $r_s$),* p-value** | **Multivariable Analysis[2] *β* [95%CI]** |
| **Profession Group** | *H* = 3.018, *p* = 0.221 | |
| AHP (ref) | | ~ |
| Medical | | -1.150 [-3.258, 0.959] |
| Nursing | | -1.00 [-3.337, 1.330] |
| **Gender** | *U* = 4002.5, *p* = 0.547 | |
| Female (ref) | | ~ |
| Male | | -0.389 [-2.410, 1.633] |
| **Age** | *H* = 9.909, *p* = 0.007** | |
| 31-50 (ref) | | ~ |
| Under 30 | | -2.145 [-5.151, 0.857] |
| 51+ | | 1.598 [-0.662, 3.858] |
| **Experience** | *H* = 3.202, *p* = 0.202 | |
| 0-10 (ref) | | ~ |
| 11-20 | | -0.742 [-2.825, 1.432] |
| 21+ | | 1.398 [-1.522, 4.318] |
| **MD Thermometer** | $r_s$ = -0.2480, *p* = 0.0002*** | 0.191 [-0.240, 0.623] |
| **Resonate with MD** | *H* = 6.584, *p* = 0.040* | |
| No (ref) | | ~ |
| Yes | | 0.161 [-2.229, 2.550] |
| Not Sure | | 0.303 [-2.723, 3.328] |
| **Burnout** | *r* = -0.686, *p* <0.001*** | **-0.556 [-7.750, -0.361] *** ** |
| **<u>Coping Resilience</u>** | $r_s$ = 0.366, *p* <0.001*** | |
| **BRCS Growth** | $r_s$ = 0.459, *p* <0.001*** | **2.183 [0.927, 3.440] *** ** |
| **BRCS Creativity** | $r_s$ = 0.360, *p* <0.001*** | |
| **BRCS Emotional Control** | $r_s$ = 0.281, *p* <0.001 *** | |
| **BRCS Adaptation** | $r_s$ = 0.069, *p = 0.315* | |
| **Turnover Intention** | *U* = 5592, *p* = 0.005** | |
| Yes (ref) | | ~ |
| No | | -0.251 [-2.288, 1.786] |
| **Absenteeism** | *U* = 281, *p* = 0.541 | - |
| No (ref) | | |
| Yes | | |
| **STS** | $r_s$ = -0.272, *p* <0.001*** | - |
| **Percentage of work week with MND** | $r_s$ = -0.027, *p* = 0.696 | - |
| **Work Setting:** | | - |
| Inpatient: | *U* = 547, *p* = 0.495 | |
| Outpatient: | *U* = 5637.5, *p* = 0.820 | |
| Community: | *U* = 451, *p* = 0.140 | |
| **Work Pattern** (Part time/Full time) | *U* = 476, *p* = 0.299 | - |

[1]Bivariate, non-parametric analyses (Man Whitney U test, Kruskal Wallis test and Spearman's rank order correlation) were conducted to examine between-group differences and associations between independent variables and the CS subscale of the ProQOL-5.

[2]Multivariable linear regression was used to further assess the impact of key variables on CS scores, adjusting for the effects of all other included predictors. Bonferroni-adjusted confidence intervals and p-values are reported to control for multiple comparisons. Statistical significance is determined at α = 0.05 and is indicated as follows*: *<0.05, **<0.01, ***<0.001.*

## Reasons Provided for Continuing to Work in MND Care in the Future

The large majority of professionals who completed the survey (*n* = 213, 94%) answered "*yes*" to the question, "*Do you see yourself continuing to work with MND in the future?*" These respondents were then asked "*why?"* in a follow-up open-text question. Their reasons were categorised and are outlined with illustrative examples in Table 5.16 below.

**Table 5.16:** Reasons Provided for Continuing to Work in MND Care in The Future

**1. Job Satisfaction and Reward – Ability to Make a Difference (*n* = 125, 60%)**

Many respondents described experiencing high levels of job satisfaction, meaning, and fulfilment in their work with individuals and families living with MND. This was primarily attributed to their perceived ability to make a meaningful difference, offer support during an immensely challenging time, and witness the positive impact of their care or interventions on patients and family's quality of life. Notably, while the work was widely viewed as rewarding, many respondents simultaneously acknowledged both the clinical complexity and emotional toll of this work.

- *'Despite the challenges it is immensely rewarding work, every day is different, and I know how much it means to people living with MND and their carers to have someone working within my role, it improves their quality of life and helps them negotiate the health and social care system, getting things in place to aid them on their journey. It is the hardest but best job I have ever done within 30 yrs in healthcare'* (MND Co-coordinator)
- '*Job satisfaction. It is a privilege to work with people at this devastating time in their lives and try to support their journey'* (Nurse)
- *'I feel that as a nurse you can really support patients psychosocially, which I find very rewarding in a population where everything is extremely devastating'* (Nurse)
- *'I really love working with this pathology and having the feeling that my patients get at least part of the help they need to live with the disease'* (Medical)
- *'Even though it is very sad that everyone on my caseload has a terminal illness, I feel I am helping them to live and communicate as best as they can for as long as they can. It can be very rewarding'* (Speech and Language Therapist)

**2. Experience, Commitment and Passion for MND Care: (*n* = 45, 22%)**

Respondents reported feeling experienced, knowledgeable, committed or passionate about providing MND care. They valued the knowledge, skills, and expertise they had developed, recognising its importance in enhancing the care of people living with MND, supporting their families, and guiding other healthcare professionals with less experience or familiarity in managing the condition.

- *'My knowledge and experience matters, and I can be of support both to patients, family and other healthcare workers'* (Nurse)
- *'I have become passionate about psychological care in MND, and so I would like to stay involved in this work. However, I do think there might be times in my career when I need to do less of the direct clinical work to regroup, then come back to it again*. (Psychologist)
- *'The varied and complex nature of ALS/MND requires support from professionals who have experience and specialism within this neurological practice. I see myself continuing to work within neurological practice, including MND for the rest of my career'* (Occupational Therapist)
- *'Requires high levels of skill from respiratory physiotherapy so I feel I can have a greater impact here than other areas of work'* (Physiotherapist)
- *'Patients need professional medical care - there are few doctors in Poland who deal with ALS. I feel like I'm needed'* (Medical)
- *'I feel committed to continuing to work with and try and support people with MND'* (Medical)

**3. Interest and Variety in the Clinical Work: (*n* = 31, 15%)**

- Respondents described enjoying the variety associated with the individualised and evolving nature of MND care and expressed a strong professional interest in the condition and the population of people living with MND.
- *'It's varied and interesting'* (Nurse)
- *'Interesting field of work'* (Physiotherapist)
- *'Continued interest in the patient group'* (Medical)
- *'Really interesting caseload'* (Occupational Therapist)
- *'The work is very varied'* (Nurse)

**4. Interest or Involvement in Research: (*n* = 31, 15%)**

Closely linked to the previous category, 31 respondents expressed that they envisioned continuing to work in this field, motivated by their sustained interest, ongoing involvement, and the opportunity to contribute to meaningful research and service development focused on expanding treatment options and improving patient care pathways for plwMND.

- '*Ability to offer research trial participation to this population and the fight to help with finding the much-needed treatments'* (Medical)
- *'The challenge to see a really effective treatment for ALS, finally'* (Medical)
- *'Interesting field clinically and in research'* (Medical)
- '*I hope that there will be a breakthrough in ALS research and wish to follow developments'* (Nurse)
- *'I have a strong motivation in ALS care and research'* (Medical)
- *'I find the professionals working in this area are some of the most passionate and committed, it is a truly multidisciplinary team with opportunities for research alongside clinical work'* (Psychologist)

**5. Multidisciplinary Team Working Environment: (*n* = 21, 10%)**

21 respondents identified the multidisciplinary nature of MND care as one of the reasons why they enjoyed working with this patient population. These respondents felt that the MDT working environment or the support from their colleagues contributed to their job satisfaction and was an enabling factor for them to continue working in this area.

- *'There is a sense of satisfaction knowing you have worked together as an MDT to ensure patients live as well as they can with the condition and ensure the quality of their life is as good as it can be'* (Nurse)
- *'I enjoy this work… and like working with the rest of the team'* (Medical)
- '*I am really happy with the team I work with, that outweighs the psychological strain of working with MND'* (Psychologist)
- *'Working in a supportive team helps to think about being able to continue working in this area'* (Physiotherapist)
- *'I have a great work environment and colleagues. I enjoy working with them and I think that "safe space" is what keeps me going'* (Psychologist)

**6. Personal Benefits: (*n* = 8, 4%)**

8 respondents identified the personal benefits they experienced from working with this population. Respondents described feelings of admiration and inspiration from witnessing how the patients and families they worked with overcame and coped with the adversity they faced. Some identified how this provided greater appreciation and perspective on their own health and personal life.

- *'The personal benefits of working with these patients outweigh the challenges'* (Physiotherapist)
- *'Factors that enable me to continue working in this role is the authenticity of patients, the commitment and resilience that I observe, I am in awe of patients and families and how they cope. It is a very grounding job, really reminds you of what is important in life'* (Psychologist)
- *'It is meaningful, and it gives perspectives to my own life'* (Physiotherapist)
- *'I find it humbling and uplifting to work with people who, while facing the most challenging of circumstances, still find meaning and purpose in life'* (Psychologist)

**7. The Nature of the Patient-Clinician Relationship: (*n* = 6, 3%)**

The nature of the relationships they formed with patients and families and the holistic approach to the care provided was identified as a factor that sustained professionals interest in working with this population.

- *'The unique relationship with patients'* (Medical)
- *'I find it rewarding to support people at such a difficult point in their lives and making a strong relationship with them and their family'* (Physiotherapist)
- *'I like them as a patient group. Build good therapeutic relationships with patients and their family'* (Physiotherapist)
- *'Creation of a special bond with patients'* (Nurse)

8. **Enjoying the Challenging Nature of the Work: (*n* = 6, 3%)**

The challenging and complex nature of MND patient care was identified as a factor that respondents enjoyed and kept them interested in continuing to work in this field.

- '*Like the complexity*' (Physiotherapist)
- *'I enjoy the work, it's a double-edged sword, the difficulty is also what I enjoy'* (Medical)
- *'I enjoy the challenging nature of the work'* (Occupational Therapist)

9. **Opportunities for Learning and Development: (*n* = 6, 3%)**

6 respondents reported how working with MND offered them ongoing opportunities for professional learning and development.

- *'I love my work with them, I learn a lot every week'* (Speech and Language Therapist)
- '*Because people with MND teach me a lot and finding better therapies is a challenge'* (Medical)
- *'It's a rewarding and challenging role that has ongoing opportunities for learning and development whilst supporting this patient group'* (Occupational Therapist)

Responses provided by *n* = 208 respondents.

## 5.3.5 Helpful and Supportive Factors for Professionals Working with MND

**Objective 6:** To measure the coping and resilience capacity of healthcare professionals working with MND and identify factors perceived as helpful or supportive in their work.

### 5.3.5.1 Resilient Coping

The Brief Resilient Coping Scale (BRCS) scores were the same across professional groups (Mdn = 15, IQR = 3). Most respondents fell in the '*medium resilient coping*' category (*n* = 125, 58%), followed by the '*low resilient coping*' category (*n* = 58, 27%) and the '*high resilient coping*' category (*n* = 32,15%) (Table 5.11). Respondents aged <30 reported lower resilient coping than those aged 31–50 (Z = 3.18, adjusted *p* = 0.004) and 51+ (Z = 3.47, adjusted *p* = 0.002). No differences were observed across gender, years of experience working with MND, or work pattern, and the BRCS total

score showed no association with the percentage of the working week spent working in MND care.

Resilient coping was weakly associated with MD intensity (MD Thermometer; $r_s$ = -0.14, p = 0.045) and secondary traumatic stress ($r_s$ = -0.19, $p$ = 0.004) and moderately associated with burnout ($r_s$ = -0.31, $p$ <0.001) and compassion satisfaction ($r_s$ = 0.37, $p$ <0.001).

Those considering leaving/changing their position in the present had lower median BRCS overall scores (Mdn: 13.5, IQR: 4) than those who were not considering leaving/changing position (Mdn: 15, IQR: 2.5; $H$ = 1822.5, $p$ = 0.051). There was no difference for those who had previously considered leaving or those who had a period of absenteeism.

#### 5.3.5.2 Helpful and Supportive Factors: Analysis of Open Test Responses

The final survey item was an open-text question asking respondents what they currently (or previously) found helpful or supportive in their roles as HCPs working with MND. Responses from both those currently working and previously working in MND services were combined and analysed using content analysis. In total, 274 unique comments from 168 respondents were coded. Helpful/supportive factors were clustered into three main categories: (1) work-related supports (2) professional attributes/characteristics and (3) personal supports (Table 5.17). Work-related supports were the most frequently cited overall, with informal collegial support ($n$ = 66, 39%) and a supportive multidisciplinary team environment ($n$ = 63, 37.5%) the most commonly reported. A summary of the categories generated from this analysis is presented in Table 5.17 below and a full descriptive analysis with illustrative quotations is provided in Appendix V.

**Table 5.17:** Helpful and Supportive Factors Identified for Working with MND

| |
|---|
| **Extrinsic Work-Related Supports**<br>• Informal collegial support – practical & emotional<br>• Working in a supportive multidisciplinary team environment<br>• Structured team reflection and de-briefing<br>• Access to clinical supervision<br>• Psychology support<br>• Relevant training opportunities<br>• Support from MND national charity organisations and international groups<br>• Organisational supports – supportive management, sufficient funding and time allocation to support MND care<br>• Relationships and open communication with patients and families<br>• Guidelines & protocols |
| **Intrinsic Professional Characteristics, Skills and Attributes**<br>• Positive reframing and recognising impact<br>• Experience<br>• Empathy<br>• Perspective taking<br>• Humour<br>• Mindfulness<br>• Creativity |
| **Personal Supports**<br>• Self-care and life beyond work<br>• Family and social network support<br>• Religion/faith/spirituality |

See full analysis and supporting quotations in Appendix V

## 5.4 Discussion

This is the first study, to the best of our knowledge, to address the issue of moral distress (MD) and measure the professional quality of life of health professionals working in MND care, HCPs from 17 different countries and 11 professional backgrounds responded to this European survey.

This study highlighted experiences of MD and the positive and negative impacts of delivering MND care on professional well-being. Despite the identified challenges associated with this work, participants demonstrated high levels of compassion satisfaction and a strong motivation to continue working with this patient population. This apparent incongruity aligns with previous research on HCPs working in end-of-life care, which highlights how HCPs often experience their work as simultaneously deeply rewarding and stressful, experiences that are not mutually exclusive but frequently coexist (Bowden *et al.*, 2015; Stokar and Pat-Horenczyk, 2022) . The findings presented above will be considered in greater depth throughout this discussion section.

### 5.4.1 Moral Distress

#### The occurrence and intensity of moral distress in healthcare professionals working with MND

67% of respondents reported that the concept of moral distress (MD) resonated with their experience of working with MND. Recognition of MD increased by 20% following the provision of a description of the concept, indicating that some professionals were experiencing MD without previously identifying it as such.

While recognition of MD was common, scores on the MD Thermometer indicated generally low overall intensity. A similar pattern was reported by Mehlis *et al.* (2018) in their study of oncologists and oncology nurses involved in end-of-life care decision-making. In the present study, most respondents rated their levels of MD over the previous two weeks as either *mild* (21.5%) or *uncomfortable* (17.5%), while only 10% reported experiencing *no distress* during that period. These findings suggest that

although MD is relatively prevalent, it does not always reach highly distressing levels. This may reflect the influence of factors such as adaptive coping mechanisms, moral resilience, or supportive team cultures, which have been shown to help clinicians navigate ethical tensions and mitigate distress, even when moral conflicts or stressors cannot be fully eliminated (Rushton, 2017; Ventovaara *et al.*, 2021).

These findings may also highlight limitations of the MD Thermometer tool in capturing the chronic or cumulative dimensions of MD (Houle *et al.*, 2024). Repeated exposure to morally challenging situations may reduce the intensity of immediate emotional reactions, even though the underlying ethical tensions remain unresolved, leading to a form of latent or normalised moral residue. According to the moral residue and crescendo framework (Epstein and Hamric, 2009; See Section 1.7, Moral Distress), coping strategies may alleviate immediate distress but do not necessarily prevent the gradual accumulation of unresolved moral strain that can persist beneath the surface of everyday practice. Over time, this latent distress may build incrementally with each subsequent moral or ethical challenge, subtly elevating clinicians' baseline level of moral residue. Although individual episodes of MD may appear mild, their cumulative effect can erode moral integrity, emotional well-being, and professional fulfilment, and manifest later as burnout, disengagement, or a diminished capacity for empathic patient and family care (Litz *et al.*, 2009; Dean, Talbot and Dean, 2019). This framework underscores the importance of early recognition and proactive management of moral stressors within the workplace to prevent cumulative harm, even when such events appear only mildly distressing at a single point in time.

Consistent with Mehlis et al. (2018), substantial interindividual variation was also observed in these findings, with one-quarter of respondents reporting levels of MD ranging from "*distressing*" to "*intense*" within the previous two weeks. Although the median MD Thermometer score indicated mild-uncomfortable levels overall, a substantial proportion of professionals reported considerable distress at the time of survey completion. These individuals represent a priority group, likely in need of targeted support, to resolve episodes of distress, promote recovery, and sustain their well-being in the workplace.

### Factors contributing to moral distress in healthcare professionals working with MND

No significant demographic or work-related variables were identified as significant predictors of MD intensity in the multivariable analysis. Although bivariate analyses indicated higher MD scores among female professionals and those spending a greater proportion of their working week in MND care, these associations did not remain statistically significant after adjustment for confounding variables and therefore require further validation.

Based on insights from focus group data (Phase Two), 24 statements were developed to reflect potential sources of MD specific to working in this clinical context. These statements represent situations in which multilevel barriers, spanning the professional, patient or condition, family, team, and organisational or system level domains, prevent clinicians from delivering care consistent with their professional judgement for plwMND and/or their families. Categorising potential contributors to MD in this way enables a more nuanced understanding of its origins and facilitates the prioritisation of targeted strategies for mitigation. This approach also aligns with frameworks proposed in previous research (Epstein *et al.*, 2019; Maffoni *et al.*, 2019). Survey results indicated that the majority of the situations presented (75%) were endorsed by more than half of respondents, highlighting their relevance in reflecting the experiences of professionals working with this patient population. Notably, situations at the organisational or system level were not only the most frequently encountered but also perceived as the most distressing barriers to providing adequate MND care by survey respondents. This pattern aligns with findings from studies in other clinical areas and further underscores the substantial influence of structural and institutional barriers on the experience of MD (De Veer *et al.*, 2013; Beadle *et al.*, 2024; Vinckers and Landeweer, 2025).

The top five clinical situations that were most frequently experienced in this cohort will be discussed in further depth, however challenges across all proposed levels were endorsed, highlighting the multifactorial nature of MD, and further supporting

the need for multilevel, context specific solutions to mitigate its negative consequences in practice (Amos and Epstein, 2022).

The situation most frequently experienced and rated as most distressing across all professional groups was witnessing patients struggle while waiting for essential aids, devices, or services. This underscores the time-sensitive nature of MND care, in which clinicians must anticipate and respond rapidly to evolving needs while also navigating patients' varying readiness or abilities to engage in decision-making (Hogden *et al.*, 2012; McConigley *et al.*, 2014). Misalignment between existing service pathways and the rapid progression of the disease, can limit clinicians' ability to meet patients' needs effectively. The fact that 89% of respondents experienced this situation suggests it is routine, rather than an exceptional, feature of MND care. The disconnect between the urgent and often intensive needs of the person and the system's limited responsiveness or capacity to meet the urgency of these needs creates an ethical tension, placing clinicians in situations where they recognise preventable suffering yet lack the authority, means or capacity to effectively intervene. The inability to fulfil one's professional and moral obligation to alleviate suffering represents a core dimension of MD and supports Molinaro's (2025) argument that professionals cannot deliver effective or ethical care within systems that undermine their capacity to do so.

Witnessing individuals receiving unequal access and levels of service depending on the region where they lived, was rated as the second most often experienced and distressing situation across all professional groups. This inequity may reflect disparities in generalist provider confidence in managing MND across regions (McConigley *et al.*, 2014), logistical challenges associated with accessing specialist services for those with advanced disease or living in rural/remote areas (Velaga *et al.*, 2023), and broader systemic inconsistencies in how services are structured and resourced across geographical regions. Such inequities give rise to a clear ethical tension when geography determines the quality or timeliness of care received, and professionals witness, but feel powerless to change, the structural barriers that perpetuate these disparities. This situation was also reported as a significant challenge for those working in MND specific services in Phase Two of this research,

who described the emotional strain of supporting patients across wide geographical areas and observing the inequities in access to care within the Irish healthcare system. The close and sustained relationships formed with plwMND and their families may further intensify this distress, as clinicians directly witness the tangible consequences of disparities in care provision. Addressing these inequities will require service-level innovations, such as telehealth, training and capacity building, and streamlined referral pathways, to ensure equitable access to care and more consistent resource allocation across regions, thereby reducing the impact of so-called "*postcode lotteries*" on patients, families, and HCPs alike.

Interestingly, while organisational or service-level barriers were the most frequently experienced and distressing situations endorsed, few professionals identified supports at this level. This mismatch may reflect a deeper sense of powerlessness among HCPs regarding their ability to influence or reform the systems in which they work. The disconnect between the sources of distress and effective system-level solutions may foster feelings of helplessness or resignation, particularly when structural barriers persist despite ongoing challenges in delivering effective care. This finding aligns with broader evidence that the causes and triggers of MD are multifactorial and deeply shaped by contextual and organisational factors (Beadle *et al.*, 2024). Nevertheless, existing responses to MD often remain focused on individual or peer-level strategies, such as education, resilience training, or emotional support, while systemic and organisational root causes of MD remain largely unaddressed (Imbulana, Davis and Prentice, 2021; Morley *et al.*, 2021; Molinaro, 2025). To meaningfully address MD in this context, there is a clear need for structural interventions that both empower HCPs to act in accordance with their professional judgement and enhance organisational capacity to recognise and respond to the unique challenges of working with MND populations.

Barriers to effective care delivery at the patient, condition, and family level were the next most frequently identified across all professional groups. At the family level the most common and distressing situation involved professionals feeling unable to alleviate caregiver burden because of service capacity constraints and the absence of accessible, dedicated supports for families. This finding is consistent with existing

literature demonstrating that MND caregivers experience substantial unmet needs and receive limited formal support (Schischlevskij *et al.*, 2021; Knudsen and Nikolajevic-Pujic, 2025). Family caregivers play an indispensable role in the day-to-day management of MND, frequently providing intensive and complex care, particularly as the disease progresses (Conroy *et al.*, 2021). Clinicians often rely heavily on these caregivers to implement and sustain care plans; however, this reliance can become problematic when caregivers are overwhelmed, exhausted, or struggling to manage their own grief and distress in response to the patient's deteriorating condition (Schischlevskij *et al.*, 2021). In such circumstances, professionals may find their capacity to introduce new interventions or adapt existing care plans severely constrained (Walls *et al.*, 2024). This situation creates an ethical tension for clinicians, who must balance the needs of the patient with the limited capacity of an already strained caregiver, leaving them feeling powerless to adequately support either party. These findings highlight the pressing need for targeted, accessible, and sustained support structures for MND caregivers. The effects of MND extend far beyond the individual living with the disease, profoundly impacting family members who often assume primary caregiving responsibilities. Strengthening supports for informal caregivers is therefore not only vital for their psychological and physical well-being but also essential for enabling HCPs to deliver effective, compassionate, and sustainable family-centred care. By positioning caregiver support as a core component of the management of MND, healthcare systems can better support ethical care by recognising caregiver burden and supporting the delivery of holistic patient and family-oriented care.

At the patient and condition level, the most frequently encountered situations were witnessing pain or distress from difficult-to-manage symptoms (70%) and difficulties meeting physical care needs resulting from challenges with psychological adjustment (71%). These situations reveal a fundamental ethical tension between clinicians' commitment to alleviating suffering and the limitations imposed by an incurable, progressively deteriorating condition. Professionals working with plwMND must continually navigate the delicate balance between respecting patient autonomy and values while providing what they consider to be clinically appropriate

and compassionate care. Ethical conflict and uncertainty can further arise when these priorities diverge between HCPs, patients, and families. Decision-making in MND is inherently triadic, involving ongoing negotiation between patient autonomy, family expectations, and professional duty (Hogden *et al.*, 2011, 2012). Conflicts often arise from the absence of a clear, shared moral framework within which these competing interests can be reconciled. In MND care, such dilemmas are largely unavoidable due to the disease's irreversible and rapidly progressive trajectory, its impact on cognition and communication, and the emotionally charged decisions it demands. Incurable conditions bring to the surface the limits of medicine and the moral complexity of care, where doing "*the right thing*" is rarely clear-cut (Schofield *et al.*, 2021). Often the course of action that aligns with one ethical principle, compromises another and clinicians are often required to act within uncertainty and manage the emotional consequences of witnessing suffering they cannot fully prevent (Pavlish *et al.*, 2015).

Consequently, while system-level strategies to address MD remain important, there is also a need for targeted interventions that support clinicians ethical reasoning and opportunities to recognise and process their emotional responses to ethically challenging circumstances (Rushton, Kaszniak and Halifax, 2013). Cultivating supportive and open interdisciplinary working environments, where HCPs feel safe to discuss moral and ethical challenges, has been identified as an effective strategy for reducing the impact of ethical uncertainty and MD (Morley *et al.*, 2021). Perni (2017) in an editorial on addressing MD, supports this opinion, stressing the need for more open discussion about '*the disconnect between our ideals and the realities of medical practice'*. Additionally, open and supportive workplace cultures have been shown to mitigate the negative effects of MD and serve as a catalyst for positive outcomes, including the development of both moral resilience and professional growth (Morley *et al.*, 2021).

### Moral Distress: Differences Between Professional Groups

Recognition of MD varied by professional group, with higher levels reported by AHPs (75%) and nurses (70%) compared to medics (56%). Similar patterns have been observed in other studies, where physicians consistently report lower levels of MD than their nursing or allied health counterparts (Whitehead *et al.*, 2015; Dodek *et al.*, 2016; Neumann *et al.*, 2018; Epstein *et al.*, 2019). This difference has been attributed to medical professionals often having less sustained, direct contact with patients, thereby reducing exposure to the emotional and ethical complexities of ongoing care (Whitehead *et al.*, 2015; Dodek *et al.*, 2016). Paddison (2016) however offers an alternative interpretation, suggesting that cultural norms within the medical profession, particularly the discouragement of emotional expression, may also contribute to lower reported levels of MD.

In the present study, it is notable that relatively fewer medical professionals identified with the experience of MD, despite working in MND care where the absence of curative treatments imposes significant clinical constraints on care. Across Europe, Riluzole remains the only licensed therapy for all forms of MND, offering only modest survival benefits, while Tofersen, approved in 2024 for the rare SOD1 subtype, applies to approximately only 2% of the patient population (Brown *et al.*, 2021; O'Brien and Shaw, 2024). Eight medical respondents in this study described the lack of effective therapeutic options as contributing to feelings of professional futility and helplessness, with several indicating that this had prompted contemplation of leaving their roles. Over half also reported difficulty sustaining hope and optimism in the absence of curative treatment options, reflecting findings by Anestis *et al.* (2021), who also identified the profound emotional burden clinicians experience when they are unable to offer hope through tangible medical interventions. However, the majority of medical professionals in this sample were highly experienced (70% with more than 10 years of MND care experience) and may therefore have developed advanced communication and coping strategies, alongside a strong sense of professional purpose. Moreover, given that one recruitment site was a network of clinician-researchers (TRICALS), it is plausible that involvement in clinical research striving for therapeutic development provided some participants with a sense of contribution and agency, that may buffer against MD.

Consistent with previous research (Allen *et al.*, 2013; Houston *et al.*, 2013; Whitehead *et al.*, 2015) we also observed variation in both the clinical scenarios most frequently encountered and those rated as most distressing by medics, nurses, and AHPs. These findings highlight the importance of recognising that the sources and expressions of MD can differ across professional groups, further underscoring the context-dependent nature of this phenomenon and the need for tailored, profession-specific strategies to address it (Amos and Epstein, 2022). The key areas of divergence between the three professional groups identified in this study are discussed in detail below.

A greater proportion of AHPs identified barriers at the professional level than nurses or medics, particularly in relation to engaging in future care planning, which was often constrained by a lack of specific training and uncertainty about the trajectory of disease progression. Notably, AHPs in this sample were generally younger, less experienced, and spent less time in direct contact with MND patients than their nursing or medical counterparts. These factors may partly explain why professional-level barriers to delivering MND care were more frequently identified by this group. AHPs also rated patient and professional level challenges, such as supporting decision-making when communication is impaired, maintaining hope in the absence of a cure, and providing effective care amid cognitive or behavioural changes, as more distressing than their nursing or medical colleagues. This pattern may reflect the rehabilitative and recovery-oriented focus of traditional AHP training, which emphasises functional improvement and patient progress, rather than the complexities of progressive decline and end-of-life decision-making. Similar observations have been reported in other contexts, for example, Disler *et al.* (2023) found that AHPs working with COPD patients expressed positive attitudes toward advance care planning but often lacked the procedural knowledge and confidence to initiate or sustain these conversations. These findings therefore suggest that professional background, training, and experience may shape how clinicians perceive and experience MD in MND care. AHPs' focus on rehabilitation and measurable patient outcomes may make them particularly sensitive to situations in which goals of care shift towards a palliative approach that prioritises maintaining

independence amid functional decline and psychosocial support, where uncertainty is high and the impact of interventions is more challenging to measure (Waldron *et al.*, 2011).

The survey results indicate that medics more frequently reported challenges related to optimal symptom management and rated these as more distressing than their nursing or AHP colleagues. Medics also identified difficulties in implementing interventions when family caregiver support was limited, highlighting a reliance on caregivers, who are often already overstretched, to facilitate symptom management. As discussed earlier, when caregivers are overwhelmed, unavailable, or in conflict with medical advice, clinicians' ability to effectively alleviate symptoms for plwMND may be further compromised. These challenges may also reflect broader systemic issues highlighted in the literature, particularly in relation to insufficient integration between neurology, palliative care, and community or rehabilitation services across the disease trajectory (Turner-Stokes *et al.*, 2007; Oliver, 2019; Grossman *et al.*, 2023). In practice, delayed or fragmented collaboration between specialties can leave medics under-supported in managing the evolving and multifaceted symptom burden characteristic of MND. Closer interdisciplinary collaboration, particularly with palliative care teams, has been proposed as a means to address these challenges by enabling shared decision-making, integrating diverse clinical perspectives, and supporting a more coordinated approach to complex symptom management (Veronese *et al.*, 2017; Grossman *et al.*, 2023; Kluger *et al.*, 2023). Moreover, MND frequently necessitates nuanced, multidisciplinary strategies to symptom management that extend beyond purely medical interventions, encompassing psychosocial, rehabilitative, and caregiver-focused considerations (Hogden *et al.*, 2017; Lau *et al.*, 2018). Medics may also face significant ethical dilemmas in balancing treatment burden against potential benefit, particularly when interventions intended to manage symptoms, such as non-invasive ventilation or enteral feeding, may compromise quality of life or introduce additional complications for both patients and their families (Barć and Kuźma-Kozakiewicz, 2020). Together, these findings illustrate the clinical and ethical complexity of symptom management

in MND care and reinforce how integrated, multidisciplinary approaches may better support clinicians navigating these challenges.

In this study, nurses identified providing emotional and psychological support to patients and families as more distressing than other professional groups. This aligns with Lyu *et al.* (2024), who highlighted oncology nurses' critical role in addressing not only physical symptoms but also complex emotional and psychological needs. However, the nurses in Lyu *et al's* (2024) study similarly reported significant challenges in fulfilling this role, owing to heavy workloads, limited formal training in psychological care, and difficulties maintaining professional boundaries while providing compassionate support (Lyu *et al.*, 2024). Nurses in the present study reported more frequent and sustained contact with patients and families than medics or AHPs, reflecting their often central role in the day-to-day coordination of MND care. This sustained proximity therefore places nurses at the forefront of witnessing emotional and existential distress. While it fosters therapeutic relationships, it also increases exposure to suffering that they may feel unable to fully alleviate. The holistic and relational focus of nursing care may heighten nurses' perceived responsibility for addressing emotional needs, creating moral tension when they feel unable to provide adequate support. Despite expertise in physical care, many nurses report feeling underprepared to manage the complex psychological and existential challenges associated with MND. Artioli *et al.* (2025), in a meta synthesis of nurses' experiences in MND care, similarly identified profound relational, emotional, and ethical challenges, including patients' existential suffering, high-stakes end-of-life decisions, and shifting family dynamics. However, nurses frequently felt ill-equipped to address these challenges due to gaps in training and institutional support for responding to the spiritual and existential dimensions of care (Artioli *et al.*, 2025).

### Moral Distress and Professional Retention

Those who identified with the experience of MD in this study were also more likely to have considered leaving or changing their position because of factors related to

working with MND. This finding is consistent with a substantial body of evidence demonstrating that MD contributes to increased turnover intention and professional disengagement across a range of healthcare settings (Austin, Saylor and Finley, 2017; Delgado-Ron *et al.*, 2024; Cerela-Boltunova, Millere and Nagle, 2025). The open-text responses from this study offer deeper insight into professionals' motivations for considering leaving their roles within MND services. Although some of these reasons align with features typically associated with MD, such as stress arising from organisational constraints, perceived futility due to limited treatment options, and challenges in team dynamics impacting patient care, others reflect broader emotional burdens. These include the cumulative impact of witnessing patient and family suffering, grief, and loss, as well as personal circumstances, such as HCPs' own experiences of bereavement, which may intensify the emotional complexity of working in this field. Therefore, while MD and exposure to ethically complex situations may explain a portion of the emotional and psychological strain experienced by professionals working in MND care, it is likely that additional personal, relational, and situational factors also contribute to their broader experience of emotional distress within this area of clinical practice.

### 5.4.2 Professional Quality of Life

#### Moral Distress and Professional Quality of Life

Consistent with previous research, findings from this survey demonstrate the proposed negative impact of MD on professional quality of life (Whitehead *et al.*, 2015; Colville *et al.*, 2019; Epstein *et al.*, 2019). In this study, higher levels of burnout and secondary traumatic stress (STS), both considered components of compassion fatigue (Stamm, 2010), were consistently associated with experiencing a higher intensity of MD. However, the cross-sectional design limits the ability to determine the temporal sequencing of these outcomes. According to the theoretical framework underpinning moral distress, exposure to morally challenging situations, coupled with perceived constraints that prevent professionals from acting in accordance with their ethical or professional values, elicits significant emotional and psychological responses (Morley *et al.*, 2019). Consequently, while causality cannot be inferred, morally distressing experiences likely play a meaningful role in the compassion

fatigue reported by respondents to this survey (Morley *et al.*, 2019; Currie and Laing, 2023; Orgambídez *et al.*, 2025). Future research should therefore employ longitudinal or prospective designs to better establish causal directionality and clarify the mechanisms underlying these associations.

### A Closer Look at Burnout and Secondary Traumatic Stress

A substantial proportion of respondents in this study scored within the moderate range for burnout (48%) and secondary traumatic stress (STS) (35%), whereas no respondents fell into the high burnout category, and only one participant met the threshold for high STS. Levels of compassion satisfaction (CS) were notably high, with no participants classified in the low CS category. These results are consistent with findings from Gerber *et al.* (2024) in paediatric palliative care professionals, and Gonçalves *et al.* (2024) in oncology and palliative care professionals, both of whom reported very low proportions of participants in the high burnout or STS ranges and similarly high CS scores. Such patterns may, in part, reflect ongoing concerns regarding the sensitivity and discriminant validity of the compassion fatigue subscales within the ProQOL-5 (Hemsworth *et al.*, 2018; Geoffrion *et al.*, 2019). De La Rosa *et al.* (2018), in a systematic review of 30 studies, cautioned that percentile-based cut-offs derived from Stamm's (2010) classifications may misrepresent the distribution of ProQOL-5 scores. Their analysis demonstrated that, across most samples, CS scores tend to exceed burnout scores, which in turn slightly exceed STS scores, a pattern that was mirrored in our data. When applying De La Rosa *et al's*. (2018) revised cut-offs, 47% of our participants would be categorised as having high STS, 45% moderate, and only 8% low, while 28% would fall within the high burnout range. These reclassifications align more closely with the qualitative findings from Phase 2 and the open-text responses from this study, which revealed significant emotional strain and perceived risks of burnout among professionals working in MND care. Overall, despite methodological limitations of the ProQOL-5, the pattern of outcomes observed in this sample appears broadly consistent with those reported across other emotionally demanding areas of clinical practice; and although cut-off

scores are provided to aid interpretation (Stamm, 2010), the use of continuous scores is recommended and were utilised in analysis of data for this study.

A recent UK study assessing burnout among MND specialist nurses and AHPs using the Burnout Assessment Tool - Core (BAT-C) and Secondary (BAT-S) dimensions found that over 80% of participants were at low risk of burnout. This was largely attributed to the high levels of job satisfaction reported within the sample (Chau *et al.*, 2025). While a recent Canadian study of ALS care providers found that 47% of participants were at risk of burnout, as measured by the Single Item Burnout Scale (SIBS), a figure that may correspond to the moderate burnout range in our own sample (Hansen, Burton-MacLeod and Schellenberg, 2024). Hansen, Burton-MacLeod and Schellenberg (2024) also reported higher burnout scores among female participants but no significant differences by age, professional role, or years of experience. Differences in outcome measures used also limits direct comparison between studies.

Interestingly, nurses in this study reported lower levels of both STS and burnout. Given the nurses who responded to this survey had more frequent MND patient contact, higher psychological burden might have been expected. However, having more opportunities to build trusting relationships with patients, often regarded as a key component of effective and satisfactory MND care (Artioli *et al.*, 2025; Lisiecka *et al.*, 2025), may offer a protective effect. The practical and relational nature of nursing care may also provide a tangible sense of purpose and efficacy, allowing professionals to see the immediate impact of their care, even as a patient's condition deteriorates (Pérez-Fuentes *et al.*, 2019; Goliroshan *et al.*, 2021) and may help explain why nurses in this cohort demonstrated lower burnout and STS, despite greater exposure to emotionally demanding care situations.

This study also found evidence suggesting that individuals in the latter stages of their careers were at higher risk of burnout, a finding that contrasts slightly with previous research by Bromberg, Schenkenberg and Brownell (2011) who examined stress in ALS clinic managers and neurologists, and found that experience was generally associated with lower stress levels. However, they did recognise that this was not universal, and some providers reported increased stress with greater experience.

This somewhat unexpected finding may reflect the cumulative emotional and psychological impact of long-term exposure to unresolved MD, the ongoing demands of MND patient care, and the impact of emotive patient and family interactions over time. Although many of the open-text responses in this study highlighted the value of knowledge and experience in navigating the complexities of this work, the high levels of professional commitment expressed may, in some cases, mask underlying symptoms of burnout. For instance, a sense of being *'needed'* or valued, together with specialised professional expertise that shapes one's professional identity, may help sustain engagement in a demanding role, even in the face of significant emotional strain. Additional contributing factors may include the increased workload and responsibilities often associated with seniority, such as mentoring junior staff or managing the most complex cases. Personal life demands, although not explicitly examined in this study, are also likely to influence experiences of work-related stress. For example, respondents highlighted factors such as family bereavement or returning from maternity leave as increasing their vulnerability to the emotional demands of MND care. Future research should explore how personal responsibilities and life factors, such as caregiving, family responsibilities, and the availability of social or relational support, intersect with professional stress, particularly in emotionally intense specialties such as MND care.

In this study, compassion satisfaction (CS) emerged as an independent protective factor against burnout, but not against STS or MD. This suggests that while deriving fulfilment from helping patients and families can mitigate some of the effects of heavy workloads and cumulative job demands, it may not fully shield professionals from the emotional toll of repeated exposure to suffering, loss, and decline, nor from the ethical dissonance characteristic of MD. This interpretation is supported by the open-text responses (Table 5.5), where many participants cited the emotional burden of cumulative patient deaths and the strain of supporting grieving families and caregivers as key reasons for considering a role change or leaving MND services. While CS likely fosters motivation and engagement in this demanding field, it does not eliminate the emotional and ethical challenges inherent in caring for patients and families facing progressive, terminal illness. Notably, higher STS scores were also

associated with a greater likelihood of having a period of work absence, further reflecting the emotional burden described by participants. Together, these findings highlight that even when CS is high, additional targeted supports may be needed to help professionals process and manage the emotional and ethical demands of MND care, as fulfilment from work alone may not be sufficient to prevent psychological strain or workforce attrition.

A particularly noteworthy finding from this study was that individuals who endorsed stronger agreement with the BRCS item, *"Regardless of what happens to me, I believe I can control my reaction to it",* reflecting greater perceived emotional regulation, reported significantly lower levels of STS. This suggests that emotional regulation may serve as a protective factor against the psychological impact of working closely with patients experiencing trauma, suffering, and end-of-life decline, a relationship supported by previous research (Singh and Hassard, 2021; Ariapooran and Abdolmaleki, 2023). Although more robust measures of emotional regulation are needed to confirm this association, these findings imply that interventions aimed at strengthening emotional regulation skills, such as mindfulness-based stress reduction, cognitive reappraisal, or emotional intelligence training, could be valuable in reducing STS and compassion fatigue for professionals providing MND care (Măirean, 2016; Robinson *et al.*, 2022; Rushforth *et al.*, 2023). Additionally, as identified by respondents to this survey, providing structured opportunities for HCPs to process and reflect on their emotional responses, through supervision, debriefing sessions, or peer support groups, may help mitigate the cumulative effects of emotional strain. These findings highlight the critical importance of addressing not only the organisational sources of distress but also equipping professionals with effective personal coping skills and strategies to navigate the profound emotional demands of caring for patients and families facing loss, grief, and suffering.

### 5.4.3 Helpful and Supportive Factors Sustaining Professionals in MND care

#### Compassion Satisfaction and Resilience

The high levels of compassion satisfaction (CS) observed in this study were further supported by open-text responses, where job satisfaction and the pride of making a meaningful difference in patients' lives were the most commonly cited reasons for professionals' intention to remain working in this field. An interesting finding was the strong predictive relationship between higher scores on the BRCS statement, *"I believe I can grow in positive ways by dealing with difficult situations",* and higher levels of CS. This suggests that a growth-oriented mindset may play a key role in sustaining professional well-being in emotionally and ethically challenging fields like MND care. In this context, clinicians' ability to positively reframe difficult situations may allow them to transform distress into meaning, reinforcing the intrinsic rewards of caregiving, a core component of CS. Open-text responses further reflected this, with several participants expressing enjoyment of the challenges and complexity of the work, while others highlighted the personal and professional growth and development opportunities it provided.

Resilient coping was typically in the 'medium' range across our sample, mirroring findings from Hansen, Burton-MacLeod and Schellenberg (2024), who also used the BRCS with Canadian ALS care providers. As expected, in the present study higher levels of resilient coping were also associated with greater CS. Participants under 30 reported lower resilient coping and in bivariate analysis also reported lower CS, suggesting these protective factors may develop with experience and perceived competence. This interpretation aligns with our qualitative findings (Phase 2), where participants described resilience and emotional coping as skills cultivated through exposure, reflection, learning, and professional growth. Resilience was moderately associated with lower burnout scores but only weakly associated with MD intensity and STS. Notably, Hansen, Burton-MacLeod and Schellenberg (2024) found no association between resilient coping and burnout in their Canadian sample. This reinforces the view that MD and related forms of emotional strain are not primarily attributable to deficits in individual resilience. Instead, these experiences more commonly arise from external, situational, and organisational factors. The moderate resilience levels observed in this sample further support this interpretation. Therefore, efforts to address this should target the root causes of the distress or

emotional strain rather than solely focusing on enhancing the resilience of individual clinicians. This approach is further supported by literature suggesting that burnout can occur even in highly resilient professionals, and that organisation directed interventions tend to be more effective than individual focused interventions in reducing burnout (Al-Busaidi *et al.*, 2025). Thus, similar to CS, our findings suggest that while resilience may offer some protection against the strain of workload and job-related demands, it is likely insufficient alone to mitigate the emotional toll of ethical dissonance and exposure to patient and family grief and suffering. Additional targeted strategies are required to address the distinct sources of emotional strain inherent in MND care.

### Helpful and Supportive Factors

Consistent with previous findings from this research, informal collegial support and opportunities to openly discuss clinical uncertainties with MDT colleagues were among the most valued forms of support identified by professionals in this study. This may reflect the fact that many of the stressors, moral challenges, and ethical dilemmas encountered in MND care are perceived as largely uncontrollable, limiting the applicability of problem-focused coping strategies and increasing the value of shared reflection and peer support. This finding further highlights the critical role of mutual understanding and trust among professional teams, given the common challenges and experiences they face in caring for these patients (Corbaz-Kurth *et al.*, 2025). Several professional attributes, such as self-compassion, empathy, creativity, humour, and perspective-taking, were also highlighted as important, alongside personal supports, emphasising the significant impact of personal life and wellness on professional well-being (Shanafelt *et al.*, 2005). Some authors have proposed models of personal-professional well-being that distinguish between factors exclusive to personal life, those unique to work life, and others that overlap, particularly in settings involving critically ill and vulnerable patients with whom professionals develop strong empathetic and compassionate relationships (Chan, Tin and Yu, 2022; Rink *et al.*, 2023). These models underscore the complexity, and all-encompassing nature of professional well-being in such emotionally demanding

roles. In line with these insights, our findings highlight the necessity for a holistic and multifaceted approach to supporting these HCPs. These supports should be comprehensive, addressing structural and workplace barriers to effective care delivery, opportunities for reflective practice and peer support, skill acquisition and professional development opportunities as well as encouragement and strategies that promote effective work-life integration and personal wellness.

## Study Strengths and Limitations

The current study achieved a high completion rate, with over 80% of professionals who started the survey completing it in full. This may reflect the relevance of the survey topic and questions to this particular population, as well as the effectiveness of reaching the appropriate target group. Additionally, the time invested in pilot testing and incorporating feedback from professionals working in the field likely helped to refine the survey content and format, reducing the risk of survey fatigue and early drop-off. A key strength of this study was the use of a mixed-methods approach, where open-text responses added depth and context to the quantitative findings, while the quantitative results helped to validate and support insights from open-text responses and previous qualitative phases.

A limitation of the current study was the inability to recruit a sufficiently large sample of HCPs who had left or changed positions due to their work with MND. The original aim was to include a sample large enough to enable comparisons on MD and resilience outcomes between those who had exited the field and those still working within it. This group remains important for future research, as their insights could offer valuable perspectives on the supports and resources that might have helped sustain them in this area of practice. There is also the potential for selection bias as those who chose to participate may have had a particular interest in wellness or professional well-being, while those experiencing the highest levels of work-related stress may not have selected to participate in an additional work-related task. A further limitation of the analysis is the heterogeneity of the Allied Health Professional (AHP) group, which comprised eight distinct professional disciplines, in contrast to

the more homogeneous nursing and medical groups. Due to small numbers within individual AHP disciplines (e.g. only 4 Dietitians participated), separate analyses were not feasible for each group, potentially masking discipline-specific differences in outcomes. Future research should therefore seek to recruit sufficiently large samples from each AHP discipline to enable more granular analysis and to explore whether subtle variations exist in moral distress, professional quality of life, and resilient coping across these individual professional groups.

The 24 statements developed to investigate antecedents of moral distress underwent only preliminary construct validity testing, which demonstrated low internal consistency. The instrument was not subjected to test–retest reliability assessment or further psychometric validation prior to administration, representing a limitation of the present study. Further psychometric evaluation and revision of this tool should be undertaken prior to its use in future research or practice. Finally, while the cross-sectional design limits inference about the direction of observed relationships and associations, it provides valuable initial data and insights into the experiences of HCPs working with MND. These findings provide a valuable starting point for future investigations and can inform future longitudinal research.

## 5.5 Conclusion

This study adds to the international evidence base on moral distress (MD) and underscores its growing recognition as a major determinant of reduced professional well-being and the loss of skilled HCPs from the workforce. It also provides context-specific insights into how MD is experienced within MND care, along with initial suggestions for addressing this issue within the MND care workforce. Given the complexity and emotional demands of working with MND, a rare neurodegenerative condition necessitating specialist, multidisciplinary management and close interdisciplinary collaboration, the findings in this survey are particularly important for supporting the future delivery of high-quality MND patient care. We found clear evidence of MD in this population, primarily arising from organisational constraints that hindered the delivery of optimal patient care. This had significant negative

implications for both professional quality of life and workforce retention. However, organisational factors were not the only contributors; multiple intersecting factors were identified as shaping experiences of MD in this cohort. The emotional toll of repeated exposure to inevitable decline, loss, grief, and death also significantly impacted emotional well-being and contributed to increased turnover intentions. While high compassion satisfaction in this sample, connected to a strong sense of purpose and professional impact, offered some protection against workload pressures, it did not counterbalance the emotional impact of witnessing MND patient suffering. Moreover, while resilient coping levels were moderately high, this appeared to develop over time, suggesting that early-career professionals likely require additional guidance and support. Those at the latter stages of their careers in MND care also experienced higher levels of burnout. Interpersonal supports such as practical and emotional support from colleagues and multidisciplinary teams were most frequently identified. Collectively, insights underscore the need for a multi-system approach to support professionals working in MND care, addressing organisational barriers to effective care delivery, bolstering team-based support, and offering individual-level interventions. Crucially, institutions caring for this patient group must recognise the emotional and psychological burden of this work and foster supportive systems and cultures accordingly.

Chapter 6 will delve further into these suggested supports and recommendations, drawing on the insights gained from the findings across all three phases of this research.

# Chapter 6: Phase Four – Integration and Discussion of Findings – Extended Pillar Integration Process

## 6.1 Introduction

The first three phases of this research have generated a rich body of data from HCPs across diverse services and disciplines, both across Ireland and Internationally. These studies have illuminated both the challenges and rewards of working with plwMND, and the personal and professional impact this work can have on the HCPs responsible for delivering their care. The findings have highlighted key barriers to providing what professionals consider to be adequate care, while also identifying opportunities for change at the team, organisational, and system levels. Important priorities for workforce development and training were identified, alongside structures and supports that may enhance and sustain individual professional well-being within this demanding field. Chapter 6 brings together findings from the preceding studies and translates them into clear, actionable recommendations for clinical practice, using the Multilevel Model of Influences on Healthcare Professional Well-Being (Penwell-Waines et al., 2018) as the conceptual framework to organise and interpret the integrated evidence.

As discussed in Chapter One, there is increased interest in recent years in HCP well-being, retention, and quality of life. In addition to high-level policy support, this increased emphasis has led to the development of several influential conceptual models of HCP well-being that offer valuable frameworks for understanding the factors shaping professionals' experiences of work (Bone, 2015; Brigham *et al.*, 2018; Penwell-Waines *et al.*, 2018; National Academies of Sciences, Engineering, and Medicine, 2019; See Appendix W). Many of these frameworks closely align with the influences on professional well-being described by participants in this research and therefore provide a valuable lens for interpreting the findings and situating them within the broader literature on workforce sustainability.

One such model is *A Framework for a Systems Approach to Clinician Burnout and Professional Well-Being* (National Academies of Sciences, Engineering, and Medicine, 2019). This framework conceptualises clinician burnout and professional well-being as outcomes of complex, interacting factors across the healthcare system, rather than as individual failings. Drawing on multilevel models from healthcare and workplace safety, the framework highlights how work design, organisational culture, leadership, and broader system pressures shape clinicians' experiences. It advocates a systems approach that combines reducing workplace stressors with actively promoting individual clinician well-being and emphasises shared responsibility across all levels of healthcare for creating environments that support both clinicians and high-quality patient care.

Similarly the *Factors Affecting Clinician Well-Being and Resilience – Conceptual Model*, developed by the National Academy of Medicine Action Collaborative on Clinician Well-Being (Brigham *et al.*, 2018), illustrates multiple domains that shape clinician well-being and resilience, emphasising the interplay between individual influences (personal characteristics, skills, and abilities) and external factors (organisational structures, regulatory environments, learning and practice contexts, broader societal and cultural conditions). The model further highlights the strong link between clinician well-being and outcomes for professionals, patients, and health systems, underscoring the importance of addressing professional well-being as a core component of healthcare quality and sustainability.

Drawing on ecological perspective thinking, The *Bioecological Model: Applications in Holistic Workplace Well-Being Management* (Bone, 2015), adapts Bronfenbrenner's (1994) bioecological systems theory as a holistic framework for examining health and well-being in organisational contexts. Employee well-being is shaped by multiple, interconnected layers of influence, ranging from the individual and immediate work environment to organisational, societal, and cultural systems. The model highlights the reciprocal interactions between employees and their environments, underscoring that workplace well-being cannot be understood solely at the individual level, but must also account for the broader micro, meso, exo, and macrosystems that shape professional experiences. By addressing well-being through these nested

systems and acknowledging the lived experience of employees, this is a framework that proposes to provide a more comprehensive and practical approach to understanding and addressing employee well-being.

Another model that similarly draws on Bronfenbrenner's (1994) ecological model is *The Multilevel Model of Influences on Healthcare Professional Well-Being* (Penwell-Waines *et al.*, 2018). This model conceptualises professional well-being as dynamically shaped by interacting factors across individual, interpersonal, organisational, and system levels. Importantly, it emphasises that no single level operates in isolation, highlighting the reciprocal influences between individuals and their working environments and the value of identifying multiple intervention points within complex healthcare systems.

Although these models differ in their conceptual emphases, they share a unifying perspective that professional well-being is shaped by multiple, interacting influences across different levels of the healthcare ecosystem. Together, these contemporary frameworks provide a robust theoretical foundation for understanding clinician well-being as a complex, multi-layered phenomenon, and in advancing approaches to workforce sustainability that extend beyond individual resilience to encompass interpersonal, organisational, and system-level influences.

To bring together the findings from the previous phases of this research in a coherent and meaningful way, a systematic approach to data integration was required. As outlined in Chapter 3, a common critique of mixed methods research concerns insufficient integration of qualitative and quantitative components, both during the research process and in the reporting and interpretation of findings (Bazeley, 2024; Skamagki *et al.*, 2024). This challenge is particularly salient in complex health and social care research, where insights are often generated across multiple methodological strands (Rana and Chimoriya, 2025). In response to increasing recognition of the need for more rigorous integration, a number of structured approaches have been developed to strengthen and formalise the process of synthesising data from multiple sources.

O'Cathain et al. (2010) describe the triangulation protocol as a method for systematically comparing findings from two studies side by side, assessing whether they demonstrate agreement (convergence), offer complementary insights (complementarity), or appear to contradict each other (dissonance). However, as this approach is designed primarily for comparing two datasets, it was not suitable for the present research, which draws on multiple sources of evidence. Moran-Ellis et al. (2006) propose *"following a thread"* as a technique for integrating qualitative and quantitative findings across several components of a study. This approach involves identifying key themes or questions in one dataset and tracing them across others to explore how they are supported, extended, or challenged. While this remains one of the few approaches that explicitly accommodates more than two data sources, it has been criticised for lacking clearly defined procedures for integration (O'Cathain, Murphy and Nicholl, 2010; Johnson, Grove and Clarke, 2019; Dupin and Borglin, 2020; Gauly, Ulahannan and Grove, 2024).

To promote greater transparency and rigour in integration processes, visual tools such as joint displays have increasingly been used to present qualitative and quantitative findings side by side, enabling a more systematic comparison and synthesis (Johnson, Grove and Clarke, 2019; Guetterman, Fàbregues and Sakakibara, 2021). Several joint display-based techniques have been developed, including the Pillar Integration Process (PIP) (Johnson, Grove and Clarke, 2019), the Mixed Methods Data Linking Activity (Fetters, et al., 2019), and the Case Comparison Table (Onwuegbuzie and Johnson, 2021). However, these approaches are also designed to integrate one qualitative and one quantitative dataset and are therefore less well suited to studies involving multiple sources.

In response to these limitations, the Extended Pillar Integration Process (ePIP) was developed as a structured and transparent approach for synthesising findings from three or more datasets (Gauly, Ulahannan and Grove, 2024). This method is particularly well suited to the present study, as it accommodates multiple data sources and incorporates visualisation tools that support the clear presentation of overarching meta-themes and integrated findings. It aligns with the pragmatic stance of this research, supporting the use of multiple forms of evidence to best answer the

research questions (Dawadi, Shrestha and Giri, 2021; Gauly, Ulahannan and Grove, 2024).

Accordingly, this chapter applies the Extended Pillar Integration Process (ePIP) to systematically synthesise findings from Phase One (scoping review), Phase Two (focus group study), and Phase Three (online survey), enabling the integration of evidence across datasets and the development of practical, actionable recommendations for clinical practice (Figure 6.1). This integrative process is further strengthened by *The Multilevel Model of Influences on Healthcare Professional Well-Being,* proposed by Penwell-Waines *et al.* (2018), which provides the conceptual structure for organising and interpreting the synthesised findings. Together, these frameworks offer a complementary methodological and theoretical foundation; the ePIP supports rigorous and transparent data integration, while the Penwell-Waines *et al.* (2018) model, guides the presentation of integrated findings across system, organisation, interpersonal and individual levels. This combined approach ensures that the findings and recommendations reflect the complex, nested influences shaping professional well-being and experiences of delivering MND care identified throughout this research.

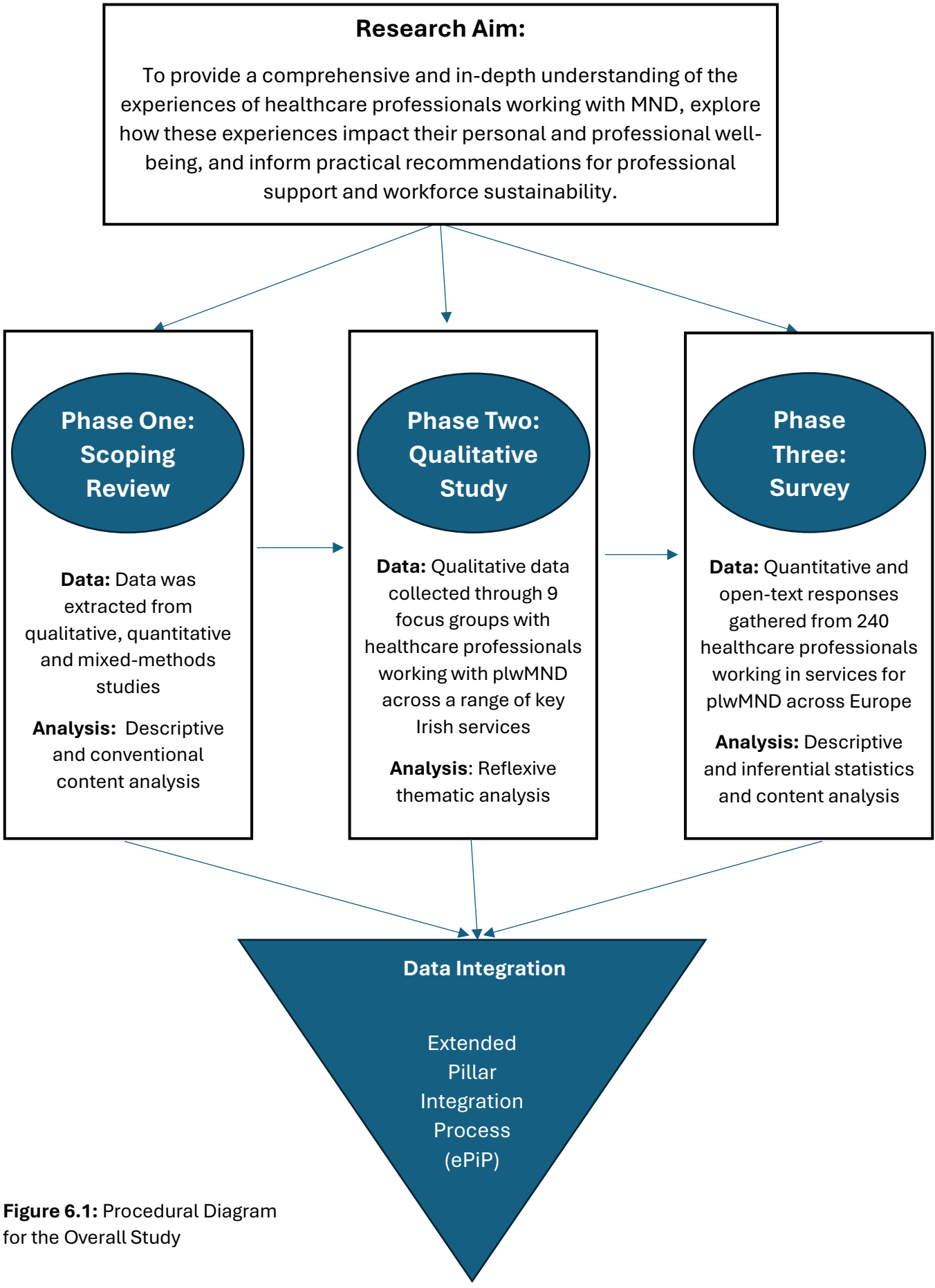


**Figure 6.1:** Procedural Diagram for the Overall Study

## 6.2 The ePIP Integration Method

The Extended Pillar Integration Process (ePIP) follows a five-stage procedure designed to guide the systematic integration of multiple datasets (Gauly, Ulahannan and Grove, 2024). Table 6.1 provides an overview of how the ePIP was applied in this research to support the integration of findings and the development of overarching themes, or *'pillars'*. An overview of how this pillar-building process was undertaken is presented in Figure 6.2 below, with complete examples provided in the joint display tables in Appendix X.

**Table 6.1:** Extended Pillar Integration Process Developed & Applied in this Research

| **ePIP Stages** | | **Description** |
|---|---|---|
| Stage 1 | Listing | • Key findings, along with the data substantiating them, were first extracted from the scoping review.<br>• Initial themes were noted alongside these findings to capture emerging patterns. |
| Stage 2 | Matching | • Findings from the focus group study were then compared with the scoping review findings.<br>• Where findings aligned, they were recorded in the same row of the table; where new ideas emerged, these were added as new rows.<br>• This process was repeated for the survey findings, with additional themes or '*pillars*' created as needed to reflect new or divergent insights. |
| Stage 3 | Checking | • The iteratively developed themes were reviewed for consistency and coherence.<br>• Similar ideas and overlapping themes were refined and grouped together. |
| Stage 4 | Development of overarching meta-themes | • The grouped '*pillars*' or themes, were then deductively organised into overarching meta-themes. The categories outlined in the Multilevel Model of Influences on Healthcare Professional Well-Being (system, organisational, interpersonal, and individual)(Penwell-Waines *et al.*, 2018) were used to structure the presentation of these themes, highlighting the multiple levels of influence on professional well-being and the layered supports required across the healthcare ecosystem. |
| Stage 5 | Write up | • The integrated findings were written up and presented under each overarching meta-theme from the system level down to the individual clinician.<br>• An overview table was developed to show all themes, meta-themes and the data sources from which they were derived (Table 6.11). This table is presented following the narrative synthesis of findings. |

This process is adapted from Gauly, Ulahannan and Grove (2024)

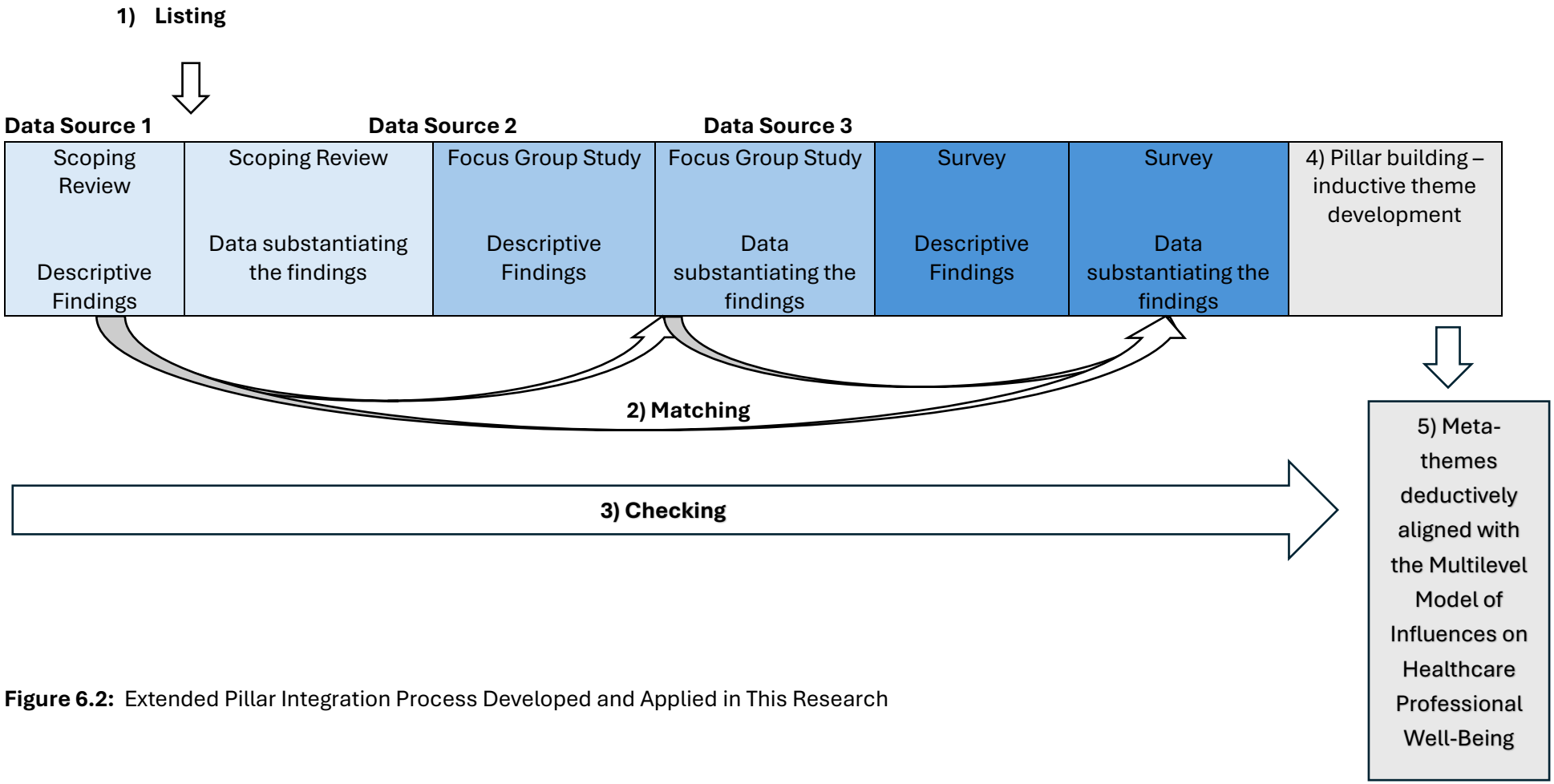


**Figure 6.2:** Extended Pillar Integration Process Developed and Applied in This Research

## 6.3 Integrated Findings and Discussion

The results of this integration phase highlight HCPs' experiences of working with individuals and families living with MND and the impact of this work on their personal and professional well-being as identified throughout this research. Solutions and interventions to address the challenges identified and to promote professional well-being within the context of MND care are then proposed. The findings are organised using a multilevel approach as outlined above, structured from the system level through to the individual level.

While the findings are organised using a multilevel ecological framework, it is recognised that many influences on professional well-being operate across levels. In this discussion, influences are positioned at the level that best reflects the primary way in which they were experienced and described by participants in this research. For example, interactions with informal caregivers were primarily identified as shaping professionals' experiences at the interpersonal level; however, the absence of dedicated services and limited time allocation to address caregivers' individual needs also influenced professional experiences at organisational and system levels. This highlights the interconnected nature of these influences and reinforces the value of a multilevel perspective for understanding professional well-being and the challenges inherent in delivering complex care within complex systems

### 6.3.1 The System

This system-level meta-theme encompasses influences on HCPs' well-being and quality of life that extend beyond their immediate organisations, capturing the broader policy, funding, regulatory, and cultural contexts that shape their experiences of work (Penwell-Waines *et al.*, 2018). Within this level, two interrelated themes were developed: care coordination and service collaboration, reflecting professionals' experiences of fragmented and inequitable care systems; and the

availability of physical and human resources required to provide appropriate care for plwMND.

## 1. Service Integration and Care Coordination: Professionals' Experiences Within Fragmented Care Systems

Across each phase of this research, professionals across all services and disciplines reported experiencing stress, frustration, isolation, and moral distress when working within poorly coordinated, fragmented, and often inequitable systems of care for plwMND. The complex and distinctive trajectory of MND posed unique challenges for professionals, teams, organisations, and systems striving to deliver person-centred and integrated care, within specific time constraints.

The scoping review highlighted communication and information sharing between teams and services as a key area for improvement. Poor interservice collaboration emerged as a major source of frustration, frequently resulting in detrimental delays in care, duplicated efforts, and increased stress for healthcare providers. Professionals with limited experience of working with plwMND emphasised the importance of timely access to specialist services for guidance, education, and support with clinical decision-making, while specialist teams highlighted their reliance on community and local services to manage essential aspects of patient care. Key barriers to effective collaboration included capacity constraints and the absence of formal communication structures between teams.

Focus group findings reinforced these results, highlighting ongoing challenges with interservice communication and frustrations associated with effectively meeting the needs of this population while navigating fragmented systems of care in Ireland. The participants in this study, emphasised the need for better awareness of each service's roles, remits, and capacities to enable more seamless collaboration and timely referrals between services. When collaboration was poor, professionals experienced heightened feelings of isolation, stress, and uncertainty. Participants also shared positive experiences of collaboration and networking initiatives (e.g. meetings between palliative care OTs and assistive technology & seating specialists) that demonstrated how teams and different services could work together more

efficiently and effectively. There was agreement that to manage the anticipatory stressors associated with care planning and effective care delivery for plwMND, proactive and ongoing communication and a shared commitment to collaboration between professionals across the boundaries of different services and organisations is required.

Survey data echoed this, >50% of respondents identified with struggling to provide interventions due to their dependence on external providers and witnessing compromised care stemming from poor communication between professionals. These circumstances can place professionals in challenging situations where care coordination or collaboration issues prevent them from meeting the needs of their patients. Findings from both the focus groups and the online survey indicated potential benefits of better integration between neurology and palliative care specialist services, as both specialties bring distinct but complementary expertise. However, how these services collaborate to address the complex and evolving symptom burden, advance care planning and support needs of plwMND and their families remains poorly defined, leading to potential gaps and missed opportunities for support between disciplines (Grossman *et al.*, 2023; Kluger *et al.*, 2023). The wider literature highlights that many people living with neurological conditions do not receive adequate support for their palliative care needs under current healthcare standards (Kluger *et al.*, 2023; Auffret *et al.*, 2025). Suggestions for improving this situation include routine screening to identify palliative care needs, the integration of palliative approaches into routine neurological care, and close collaboration between neurologists and palliative care specialists (Veronese *et al.*, 2015; Kluger *et al.*, 2023; Zacharias *et al.*, 2024).

Applying the principles of integrated care consistently across the full continuum of care for plwMND, who interact with multiple specialist and generalist services at different stages, represents a critical challenge for service planning and delivery (Zonneveld *et al.*, 2018; Lisiecka *et al.*, 2025). This need to improve coordination of care for plwMND and other rare diseases is recognised in both national and international policy frameworks. The Optimal Clinical Pathway for Adults with MND, developed by the National Neurosciences Advisory Group in the UK (2023), stresses

the importance of working across traditional health and social care boundaries to deliver truly patient-centred care for plwMND. Similarly, Ireland's National Rare Diseases Strategy (2025) calls for inclusive and integrated systems that meet the lifelong needs of those with rare conditions, emphasising the need for collaboration across primary, community, acute, and specialist services (Department of Health, 2025). These principles are further reinforced in recent European best practice guidelines for the management of MND (Van Damme *et al.*, 2024). However, our findings, consistent with recent findings from Hutchinson *et al*. (2025) and Lisiecka *et al*. (2025), highlight a persistent gap between guidance and practice. Suggesting that considerable effort is still required to support the delivery of coordinated care across the entire MND trajectory. Such support would enable professionals to provide the standard of care they recognise that patients and families require, while also mitigating the significant uncertainty and professional isolation that can arise when navigating fragmented or poorly coordinated systems of care.

Recent efforts to improve MND care coordination have shown promising benefits. Hutchinson *et al*. (2025) demonstrated that a regional multidisciplinary team improved communication between professionals and care coordination at a local level. This study similarly recognised how integrated care not only benefits patient outcomes but is also effective in managing professional stress, moral distress, and the risk of burnout associated with working within fragmented care systems. The introduction of an MND key worker or case manager has also been proposed to enhance care coordination (Bakker *et al.*, 2015; Bonnar *et al.*, 2018; Lisiecka *et al.*, 2025). However, given the geographical dispersion of patients, the diversity of professionals involved in their care, and the progressive nature of MND, which necessitates frequent and timely adjustments to care plans, adequate resourcing and careful consideration of how this role is best delivered are essential if its potential is to be fully realised.

Digital technologies also present important opportunities to strengthen communication and collaboration across service boundaries (Smaradottir, Berntsen and Fensli, 2020; Eid *et al.*, 2023). However, as identified in Phase Two of this research information sharing often depends on the capacity and willingness of

individual professionals (Hutchinson *et al.*, 2025). While the absence of shared, interoperable electronic documentation across most national healthcare systems remains a major barrier (Skeidsvoll Solvang *et al.*, 2025; International Foundation for Integrated Care, 2025), accessible digital meeting platforms offer the potential to facilitate meetings between services and enable anticipatory, parallel and collaborative care planning. Similarly, health information passports developed by MND Charity Organisations such as the MND Association (UK) (2024) and the Irish MND Association (IMNDA) (2025) offer an innovative way to centralise care plans, document critical decisions, minimise repetition, and facilitate coordination among professionals and caregivers, supporting shared goals of care for plwMND, their families and their healthcare teams.

Networking opportunities and education and training events that bring together professionals from across different services were identified in this research as playing a valuable role in strengthening collaboration between services. Such initiatives could foster stronger working relationships and enhance understanding of each other's expertise and responsibilities. Beyond professional education, networking and shared learning events can create spaces for dialogue, where staff can share challenges, exchange good practice, and develop innovative solutions to commonly encountered problems. Establishing routine events, rather than relying on ad hoc initiatives may also be helpful in establishing consistency and strengthening collaborative relationships over time as teams, processes and systems inevitably evolve and change.

A summary of the recommendations generated from the integration of findings related to care coordination and collaboration across services are presented in Table 6.2.

**Table 6.2:** Recommendations to Support Enhanced Care Coordination and Collaboration Across Services Delivering MND Patient Care

| **Recommendations:** Strengthen service integration and collaboration across services delivering MND patient care to support cohesive, multidisciplinary care and reduce the professional stress associated with working within fragmented systems |
|---|

- **Develop optimal care pathways for the management of MND** that delineates roles, responsibilities and referral points for each of the services involved across the continuum of care
- **Develop clinical guidance on the provision of neuropalliative care** and further explore how best to integrate specialist MND/neurology and palliative care services
- **Explore methods for shared communication across service boundaries** such as the use of shared documents and digital technologies
- **Further consider the role and impact of the MND key worker** in supporting care coordination and determine optimal models of service delivery and staffing within this role
- **Provide regular MND specific networking and training events** that bring together specialist, community and regional care services

## 2. Physical and Human Resources: To Provide the Level of Care Required by People Living with MND

Across all phases of this research, professionals identified that providing care for plwMND and their families often required substantially more time and resources than caring for other patient groups. Despite this, they frequently felt expected to meet complex, highly individualised, and evolving care needs without additional support or resource allocation. The Job Demands-Resources model outlines how a sustained imbalance between high job demands and insufficient resources creates conditions that increase the risk of burnout (Bakker and Demerouti, 2007). While feeling, restricted from providing adequate care due to resource limitations is a key contributor to moral distress (DeBoer *et al.*, 2021).

### Human Resources: MND Specific Services

In the scoping review, ten sources highlighted staffing shortages or high turnover as significant barriers to delivering consistent, high-quality care. Staffing vacancies contributed to inconsistent multidisciplinary team compositions and limited the delivery of essential aspects of specialist care. Focus group findings supported this, staff in specialist services noted that many professionals avoid working in MND services due to the perceived emotional and practical demands. Some of those who were working in MND specific roles, also questioned the sustainability of the career, whereas others found the role rewarding and fulfilling and reported a deep sense of professional commitment to working in this area. The impact of staffing challenges

was further illustrated in the online survey as, 58% of respondents had witnessed care for plwMND being negatively affected by staffing vacancies, while 26% of total respondents had or were considered leaving or changing their jobs because of factors related to working with MND. This was mostly attributed to the aggregated emotional toll experienced from working with loss, grief and bereavement and the burden associated with managing complex and intensive caseloads. Again, similar to focus group findings despite these challenges, the survey also revealed high levels of compassion satisfaction in this workforce, with most respondents (93%) indicating that they were likely to continue working within MND services in the future because of the personal and professional fulfilment they derived from this work.

These findings firstly underscore the need to ensure specialist MND services are adequately resourced and staffed with the recommended multidisciplinary team members and configured to meet the complex and multifaceted needs of plwMND and families. While guidance exists regarding the professional disciplines that should be represented in MND multidisciplinary clinics (Van Damme et al., 2024; NICE, 2016), no guidance currently specifies recommended staffing ratios relative to the number of patients attending each clinic. Applying population needs-based multidisciplinary frameworks could help identify gaps between service demand and configuration (Meadows *et al.*, 2025). Importantly, these findings challenge common assumptions about MND specialist work by highlighting its positive impact on professional quality of life, while also emphasising the need to recognise and support the substantial practical and emotional demands inherent in this role (See 6.3.2 The Organisation). Sustaining staff who are repeatedly exposed to loss and grief requires compassionate work environments, adequate staffing, and access to emotional well-being resources (Phillips and Volker, 2020). Providing such supportive working conditions may not only help to safeguard and retain the existing workforce but may also enhance the attractiveness of this field to prospective clinicians who might otherwise be deterred by the emotional burden and practical complexities associated with MND care.

Limited capacity as well as personnel and knowledge gaps within community and local services, were identified as a major source of stress for professionals in national

and regional MND specific services. These constraints often hindered their ability to deliver interventions critical to enhancing the quality of life of patients and families. Professionals described situations in which patients lacked access to essential community-based disciplines, such as dietetics or occupational therapy, resulting in suboptimal care, increased burden on informal caregivers, and added distress for clinicians witnessing avoidable patient or family suffering. Hence, staffing levels and capacity of community and other supporting services can also profoundly influence both the stress and moral distress experienced by those working in MND specialist roles.

### Human Resources: Non-MND Specific Services

The focus group study in Phase Two of this research was unique in that we were able to gain insight into the perspectives of those working in both MND specific (MND charity and multidisciplinary clinics) and non-specific services (primary, palliative and residential care). Participants working in non-MND specific services highlighted the substantial time and personnel demands required to provide care for plwMND. Professionals identified the increased time demand required for tasks such as effectively communicating with plwMND, building rapport, addressing multifaceted and quickly changing care needs and addressing family needs. In some inpatient wards, staff reported only having the capacity to care for one plwMND on the ward at a given a time, with the demands on nursing and care staff particularly emphasised. In both the scoping review and focus group study, a person with MND on the ward was recognised as reducing the time available for other patients, creating additional stress and ethical discomfort for staff.

A novel theme identified in the focus group study was the anticipatory stress, described by many professionals working in non-MND specific services as feelings of anxiety or self-doubt experienced prior to interactions with plwMND. These feelings were often driven by concerns about their ability to adequately meet the complexity of their care needs, as well as by previous challenging experiences. Across both the scoping review and focus group study, professionals who were new to or less familiar

with MND described a tendency to avoid these patients due to the perceived complexity of their care. Moreover, those in non-MND specific settings, while they may not have the same level of exposure to the loss of plwMND, they described forming especially close relationships with patients and families and the intensity of this involvement often resulted in the persons death having a profound personal and professional impact on them.

To address these challenges, within all services supporting plwMND attention should be given to the time and human resource allocation required to meet the levels of dependency and frequency of interactions the effective management of this condition demands. In Ireland, the Nursing Hours per Resident Day (NHpRD) model, Resource Utilisation Group IV (RUG-IV) instrument, is currently being piloted to determine safe staffing levels and optimal skill mix in care facilities (Department of Health, 2023). Such models propose to offer a more equitable and needs-based approach by aligning staffing decisions with actual care requirements rather than simple patient numbers. Beyond staffing, attention must also be given to the competence and confidence of general and regional care providers, to reduce anticipatory stress when working with plwMND. Strengthening the capacity of specialist services to deliver timely education and support to community-based teams, alongside the development of accessible, on-demand training resources and regular networking events could substantially improve confidence and competence in MND care across all settings. Ensuring that HCPs can access the right information at the right time may further alleviate some of the anxieties and uncertainties commonly reported, when supporting plwMND (Further addressed in 6.3.4 The Individual). Finally, it is essential to provide appropriate support for professionals who experience the death of plwMND, including those who may encounter such losses less frequently but who have nonetheless formed meaningful relationships and delivered intensive care throughout the individual's illness. Such support is important in enabling all HCPs to process and acknowledge their experiences of professional grief.

### Physical Resources and Infrastructure

Witnessing individuals struggle while waiting for essential aids, devices, and services emerged as the most significant potential cause of moral distress across all professional groups in the online survey and was a barrier experienced by 89% of respondents. This finding was consistently reinforced in both the scoping review and focus groups data. Psychological strain arising from system-level barriers to providing effective care for plwMND and resources limitations impacting care delivery, were also identified as factors influencing some professionals' consideration of leaving their positions in online survey open-text responses. Focus group data highlighted the frustration of repeatedly working within inadequate infrastructure, dealing with repeated delays in securing assistive devices and technologies and funding to support timely home modifications and care services. These challenges were particularly distressing given patients' high dependency and the often-avoidable suffering professionals consequently witnessed. Given the challenges that patients and families frequently face in accepting the nature of a diagnosis and making numerous decisions within a relatively short timeframe, professionals identified the importance of having easy access to essential resources so that they could be provided in line with the persons readiness to engage with them, and to avoid feelings of adding to the individuals psychological distress by needing to confront them with future realities, while they were already struggling to cope with their present circumstances.

A key finding from the online survey was that secondary traumatic stress was most strongly associated with the intensity of moral distress experienced; with delayed access to essential aids, devices and services identified as the most common distressing contributor to moral distress. This aligns with experiences of helplessness described in the focus groups, when the needs of plwMND or their families exceeded the resources available within the health service. It is clear that professionals are profoundly affected by the suffering and struggles of plwMND, in particular when systemic constraints prevent them from providing care that is consistent with their professional or ethical standards. One of the most challenging situations identified in the focus group discussions was knowing that a potential

solution existed but being unable to access or deliver it. This created anxiety and uncertainty about how to discuss potentially helpful interventions with patients and families, especially when they could not guarantee the timely provision of required resources. Administrative and financial delays frequently resulted in aids or equipment arriving only after disease progression had rendered them unsuitable, which was described as a particularly distressing situation for clinicians. These circumstances were also perceived to undermine professional credibility and the trust placed in them by patients and families. Moreover, geographic variability in resource allocation and availability introduced an additional layer of inequity and ethical discomfort, an issue that was widely endorsed by a substantial proportion (77%) of survey respondents.

Focus groups discussions highlighted significant challenges in accessing facilities and infrastructure suited to the needs of plwMND. These included securing acute hospital beds within required timeframes for procedures such as gastrostomy insertion, limited availability of respite beds in settings capable of managing the complexity of care needs, and a shortage of appropriate long-term care options, particularly for younger individuals whose needs exceeded what could be provided in the community. Professionals described being the visible face of a healthcare system unable to meet these needs or alleviate care burdens as "*soul-destroying*", noting that it strained the relationships they had worked hard to build with patients and families. This pattern was further echoed in the survey findings, with 68% of respondents reporting that they had witnessed compromised care for people with MND due to insufficient resources or bed capacity.

Interestingly, although barriers to timely access to aids, devices, and services were consistently described as distressing challenges, few respondents identified effective supports to address these issues at any phase of the research. As discussed in Chapter 5, this may reflect a deep sense of powerlessness among staff working within systems that repeatedly fail to provide the conditions needed for timely, person-centred care. MND imposes exceptionally high demands on both professionals and services, yet the findings from this research suggest that resource

allocation often does not match the condition's complexity and intensity, with significant implications for professional well-being.

Addressing this mismatch requires action on multiple fronts. While access to physical resources is one aspect, services and organisations responsible for delivering MND care must also advocate for increased funding and formal recognition of the unique needs of plwMND and other progressive neurological conditions. Streamlining bureaucratic processes and ensuring widespread awareness of the time-sensitive needs of this population is critical, as delays in securing essential aids, devices, funding and services not only compromise patient safety and quality of life but also place profound emotional and ethical strain on healthcare providers who often know what is needed but lack the authority or means to deliver it. MND charities currently play a vital role in bridging these gaps, providing equipment loan banks and financial support for aids and services that are otherwise difficult to access through national health systems. The support offered by these organisations was frequently recognised as a valuable resource by professionals in the online survey. However, many of these charities are underfunded and dependent on fundraising efforts, limiting their ability to fully meet the scale of demand. It is however important that all professionals working with plwMND are aware of the resources these organisations offer and know how to access them promptly when needed.

Ultimately, ensuring that HCPs have access to adequate physical, human, and time resources, alongside appropriately equipped clinical environments, is essential for both the delivery of high-quality care and the sustainability of the workforce. In the absence of such investment, professionals are required to operate within systems that intensify moral distress and burnout, thereby placing the retention of skilled staff in this already demanding field at risk. A summary of the recommendations generated to support professionals with the human and physical resources identified across this research as necessary to adequately respond to the unique, time-sensitive and intensive care needs of people living with MND is presented in Table 6.3.

**Table 6.3:** Recommendations to Ensure Adequate Human and Physical Resources for MND Care

**Recommendations:** Ensure professionals are supported with adequate resources and infrastructure to support the demands of MND patient care delivery

**Human Resources:**

- Ensure specialist multidisciplinary teams are adequately resourced with all core MDT members
- Use population needs-based frameworks to assess service demands and determine optimal staffing levels and team configurations
- Enhance the capacity of MND specialist teams and services to support and provide training and education to community and regional teams as required
- Ensure availability of emotional support for staff working with plwMND in both specialist and non-specialist roles (see more detail in section 6.3.2 below), to sustain their ability to remain working in this clinical area overtime

**Physical Resources:**

- Advocate for funding, resources and administrative systems that reflect the intensive and time sensitive needs of plwMND
- Expand access and awareness of dedicated services provided by MND charity organisations such as equipment loan services, homecare, counselling and ensure that these services evolve in line with gaps in service and needs identified by MND patients, families and care providers
- Advocate for the development of dedicated MND infrastructure and the formal recognition of the complex and evolving needs of plwMND within existing health and social care systems**.** Examples include protected acute-care capacity, accessible respite, home-care services and residential care facilities equipped to manage advanced physical disability, communication impairment, and ventilatory support through appropriately skilled multidisciplinary teams.

## 6.3.2 The Organisation

This organisational-level meta-theme encompasses influences on HCPs' well-being and quality of life that arise within their immediate workplace environments. These organisational factors play a critical mediating role between system-level conditions and individual experiences of work. They include factors such as organisational policies and procedures, patterns of workload distribution, institutional values, workplace culture, and leadership and management styles (Penwell-Waines *et al.*, 2018).

Across this research, organisational level influences on professional well-being included the extent to which the emotional and practical demands of MND care were acknowledged and supported by leaders and managers in the organisations that they worked in, and the availability of appropriate resources, processes, and organisational policies that supported them in delivering the level and intensity of care that was required by plwMND and their families.

### 1. The Role of Workload Flexibility and Autonomy in Supporting Professional Well-being

In addition to having adequate resources and services to meet the intensity of care required by plwMND, this research highlighted the importance of flexible workplace structures and cultures that enable professionals to respond to the unpredictable and evolving needs of patients and families, while also managing the workload and emotional demands. In Section 6.3.4, cognitive flexibility and adaptability are further highlighted as individual-level skills that may help professionals to work within the uncertain and evolving nature of MND care; however, these capabilities also need to be supported by workplaces that facilitate flexible service delivery that is aligned with patients' often urgent and changing needs.

In the focus group study, a number of professionals highlighted that having temporal flexibility within their work schedules, the ability to take breaks after emotionally intense interactions, or manage the pace of their workload, was instrumental in helping them cope with the emotional demands of their roles. Those working in MND charity organisations in particular, recognised the benefits of working within a service that was designed specifically around the needs of plwMND, and of leadership that understood the unique challenges associated with this population. Having autonomy over their caseload planning and management was identified as a particular benefit, allowing them to balance visits for more challenging cases, with those that were more familiar or had less challenging needs to address.

Across inpatient settings the focus group participants also emphasised the need for understanding and flexibility within services to distribute and share the workload across wards, teams, and individual clinicians. They highlighted the importance of feeling able to seek support from managers and organisational leaders when aspects of a person's care became particularly demanding or "*overwhelming*". Flexibility and autonomy with time management were also highlighted, across both the scoping review and focus group findings, as essential given the unpredictable and variable nature of MND and differences in how individuals and families cope with the diagnosis and disease progression. These factors can make it difficult to anticipate the time required to provide adequate support. Although it was not one of the most highly rated scenarios in the online survey, 42% of respondents did identify with having to prioritise only certain aspects a person's care due to limited time during appointments. Additionally, difficulties in providing care in a prompt or timely manner were identified as affecting both psychological well-being and intentions to leave their role in an MND service.

Lack of flexibility in caseload and workload management, as experienced by those working within the ATSS service (focus group study), was reflected in organisational scheduling policies that restricted their ability to prioritise urgent cases and limited their autonomy in planning and facilitating outreach visits. As a result, they felt they were not always able to respond adequately to the needs of some plwMND and their families, particularly those in certain regions of the country, which contributed to feelings of guilt and frustration. Similarly, busy multidisciplinary outpatient clinic environments, characterised by limited appointment time and little control over clinic capacity, contributed to feelings of being unable to fully address patient and family needs. Although again this was not among the highest rated scenarios in the online survey, 45% of respondents similarly identified with difficulty meeting the needs of plwMND or their families due to limitations imposed by organisational policies or procedures. These findings highlight how restrictive workplace policies and procedures can directly constrain the care professionals are able to provide and undermine their sense of effectiveness and fulfilment at work.

The protective benefits of professional autonomy and flexibility in work schedules on professional well-being have been identified in a number of studies (Jung *et al.*, 2024; Ibrahim *et al.*, 2025), and are key in helping healthcare workers manage the emotional and practical demands of complex care environments (Razai, Kooner and Majeed, 2023). The ability to adjust workloads, pace interactions, and balance caseload intensity allows professionals to regulate their exposure to emotionally charged situations and recover when needed. When staff have greater control over their schedules and caseloads, they report reduced stress, improved well-being, and an enhanced ability to remain engaged in delivering high-quality, compassionate care (Ryan and Deci, 2020; Kovbuz, 2025). Thus, these findings suggest that organisational leaders and managers should consider structures that allow staff flexibility and control in managing their workload, where possible.

## 2. Recognising Professional Grief and the Emotional Burden of MND Care in the Workplace

The emotional and psychological impact for HCPs working with plwMND and their families was identified across all phases of this research. While certain service and organisational level barriers were identified as limiting professionals' ability to meet patient and family needs or alleviate suffering in line with professional and ethical standards, distinct features of working with MND were also described as having a profound impact on HCPs involved in this care. These include the incurable disease trajectory, progressively disabling and often distressing symptoms, and continual exposure to loss, grief, and family distress, factors that cannot be mitigated through system level change alone. The relentless practical and emotional demands associated with ongoing deterioration and frequent changes in patients' conditions further intensify this burden.

Although moral distress contributed to the emotional and psychological strain experienced by professionals working in MND care, and Phase Three identified several potentially modifiable sources of this distress, it did not, in isolation, account for the levels of compassion fatigue and burnout observed in the survey. Instead, this

research demonstrates that these outcomes are shaped by a wider constellation of personal, relational, and situational factors, underscoring the deeply multifactorial nature of HCPs' emotional and psychological distress in MND care

One of the most notable findings from the focus group study was the depth of relationships professionals developed with plwMND and their families, a factor that appeared to intensify the emotional and psychological demands of this work. The scoping review found that relationships with plwMND and their families were often more intensive and involved than other patient populations. The focus group study, built on these findings, and provided much deeper insight into the relational dynamics and complexities for professionals working with plwMND and their families. In this study, participants described how this work required deep personal engagement to build trust and rapport and to provide consistent support throughout the many stages of loss, change, and adjustment. These therapeutic relationships could challenge conventional professional boundaries, as professionals developed deep empathy for patients' situations while needing to balance this with their professional roles and responsibilities. Continuity of care and strong therapeutic relationships were viewed as essential for delivering holistic, person-centred care and were identified as a determinant of job satisfaction. However, sustaining this high level of relational engagement demanded substantial emotional labour, particularly as professionals witnessed progressive functional decline, increasing dependency, and escalating symptoms.

Certain cases were described as particularly triggering across both in the focus group and online survey findings, especially those involving younger patients, rapid disease progression, complex social circumstances, or situations that personally resonated with the professional. Participants characterised MND as a "*confronting*" condition, suggesting that its trajectory can prompt professionals to reflect on their own fears around disability, dependence, and death, particularly when patients' life circumstances parallel their own. Similar experiences have been documented among other HCPs working in end-of-life care contexts (Clare, Elander and Baraniak, 2022; Alhusamiah and Zeilani, 2025). However, the profound disability and emotional suffering associated with MND, together with the fact that the condition

affects individuals across the adult lifespan, appear to heighten clinicians' awareness of human vulnerability and the fragility of life. The deep connections formed with patients and families, built through sustained presence and support during a period of significant adversity in their life, was described as deeply meaningful but also among the most emotionally demanding aspects of the role.

The loss or death of patients was also identified as having a significant emotional impact on professionals. Many participants identified that they were not expected, encouraged, or given space to grieve within the workplace and instead relied on informal support from colleagues or their own personal coping strategies outside of work to manage these emotional demands. In the online survey some participants identified the emotional challenges associated with working with a patient population in which death is an inevitable outcome, and in the focus group professionals also described uncertainty about how best to acknowledge or process the deaths of patients, particularly those with whom they had been closely involved. Together, these findings indicate a lack of clear organisational norms and supports for professional grief and loss within services providing MND patient care.

In the online survey, compassion satisfaction (CS) was identified as an independent protective factor against burnout, but not against secondary traumatic stress (STS). This important finding suggests that while feeling fulfilled by helping plwMND and their families may buffer the effects of workload and job demands, it does not sufficiently shield professionals from secondary exposure to the suffering and distress of MND patients and families. Open-text responses gathered in the survey reinforced this, with participants describing the cumulative emotional toll of patient losses, repeated exposure to death, and supporting families through grief as the most common reasons for considering a role change, leaving an MND service, or needing to take a period of time off. These findings again underscore the importance of identifying and introducing strategies and interventions in the workplace that enable professionals to process and cope with the demands of working with the levels of loss, grief, suffering and emotional distress they are exposed to when working with these patients and families, as personal fulfilment or enjoyment of the work alone appear to be ineffective in managing these demands.

The literature on professional loss and grief in healthcare aligns closely with these findings, highlighting how clinicians often struggle to find the time and space to process grief and face strong normative constraints on expressing it in the workplace (Funk, Peters and Roger, 2017). Institutional culture plays a critical role in shaping these experiences, with the potential to either mitigate or to exacerbate professional grief. In some settings, an unspoken expectation that "*death is part of the job*" can foster a culture of silence, where staff feel compelled to move on quickly without acknowledging their own emotional responses (Phillips, Trainum and Thomas Hebdon, 2025). This lack of recognition can render professional grief particularly isolating (Phillips, Trainum and Thomas Hebdon, 2025). These cultural pressures are further compounded by heavy and demanding workloads, which leave little opportunity for reflection or emotional processing and reinforce the expectation that patient care must take precedence over professionals' own emotional needs (Crape *et al.*, 2025).

Papadatou's (2000) model of healthcare professionals' grieving processes offers a valuable framework for understanding how clinicians experience and adapt to grief in the context of repeated patient deaths. She conceptualises professional grief as an ongoing, cyclical, and interactive process, in which individuals oscillate between loss-oriented reactions, such as sadness, anger, or guilt, and restoration-oriented responses focused on coping, adjustment, and continuing in their professional roles. The model highlights that these grieving processes are shaped by a combination of personal factors (including experience, beliefs, and coping resources), relational factors (such as support from colleagues and the nature of patient–professional relationships), and situational influences (including the frequency of deaths, the suffering witnessed, and organisational culture) (Papadatou, 2000).

Over time, professionals may adapt by integrating loss into their identity and finding meaning in their work, yet unsupported grief can lead to burnout, compassion fatigue, and emotional exhaustion (Papadatou, 2000). Accordingly, Papadatou emphasises the importance of organisational support, supervision, peer acknowledgement of loss, and training in coping and self-care as central to sustaining professionals' well-being while enabling them to provide compassionate

care (Papadatou, 2000). Empirical evidence supports this position, indicating that clinicians cope more effectively and experience less emotional exhaustion when institutions provide structured supports such as team debriefings, counselling, and peer support (Gray and Kim, 2017; Phillips and Volker, 2020; Phillips, Trainum and Thomas Hebdon, 2025). Yet, consistent with the findings of this research, many studies report that HCPs do not feel adequately supported by their organisations in managing professional grief (Phillips and Volker, 2020; Phillips, Trainum and Thomas Hebdon, 2025).

In healthcare, culture and leadership are closely intertwined, with compassionate leadership increasingly recognised as central to supporting professionals facing grief and the emotional demands of end-of-life care (De Zulueta, 2015; Hewison, Sawbridge and Tooley, 2019). Rooted in relationships, attentive listening, empathy, and proactive support, this approach fosters psychological safety and enables staff to express vulnerability and seek help without fear of judgement.

Evidence suggests that compassionate leadership enhances staff well-being, resilience, and engagement, while also improving the quality of patient care (West, 2021). By promoting practices such as supervision, debriefing, and access to emotional support, it offers a practical means of shifting organisational cultures away from silence and emotional suppression toward openness and shared support. Embedding compassionate leadership within services caring for plwMND may therefore play a particularly important role in sustaining professionals exposed to high levels of loss, grief, and emotional strain.

### Access to Effective Clinical Supervision

Professionals in both the focus groups and online survey recognised the benefits of having access to clinical supervision. A number of different formats for this were suggested. Those newer to working with these patients, identified the benefits of access to senior colleagues, for clinical guidance, to enhance professional development and to reduce feelings of uncertainty. Others identified the value of supervision as a space to address the emotional burdens of the work. Respondents in the online survey additionally identified benefits of group supervision, peer

supervision and supervision provided by psychology colleagues. The most appropriate format of professional supervision is likely to vary depending on the service, structure and available resources within respective organisations. However, regular, protected, and formal supervision structures should be available to all professionals working with this patient population. Organisational culture, staffing levels, and workforce pressures can significantly affect employees' ability to effectively engage in supervision, and it is therefore essential that organisations and clinical leaders remain cognisant of these barriers to participation (Rothwell *et al.*, 2021).

A wide range of models of clinical and professional supervision have been identified in the literature, and future work should consider which approaches and modalities are best suited to different groups of professionals working with MND. Proctor's model (1986) outlines three core functions of supervision; formative function (developing skills and knowledge), the normative function (ensuring safe, ethical, and accountable practice), and the restorative function (supporting supervisees' well-being). This model is widely used across healthcare and counselling because it offers a balanced framework that addresses both professional development and emotional support (Litherland *et al.*, 2023) . In addition, Rønnestad and Skovholt's Lifespan Model and Stoltenberg and Delworth's Integrated Developmental Model provide helpful guidance by recognising how supervision needs shift with experience (Stoltenberg, McNeill and Delworth, 1998; Skovholt and Rønnestad, 2003). For example, novice professionals often require strong formative support, such as skill development, grounding techniques, and help managing countertransference, whereas more experienced practitioners benefit from reflective opportunities to explore meaning, resilience, and professional identity (Keane *et al.*, 2020). This aligns with the findings reported in Section 6.3.4 below, regarding the influence of age and level of experience on professionals' support needs

Effective clinical supervision provides essential support for professionals working in emotionally complex areas, offering structured opportunities for reflection, guidance, and emotional processing (Edmonds *et al.*, 2015; Beavis, Davis and McKenzie, 2021). Through supervision, professionals can better manage the personal

impact of repeated exposure to suffering, loss, and bereavement, while also strengthening confidence in decision-making and navigating professional boundaries (Keane *et al.*, 2020). Hewison, Sawbridge and Tooley (2019) highlight that a central challenge for leaders in end-of-life care is supporting staff to negotiate the overlap between professional responsibilities and personal involvement with patients and families.

Despite its recognised value, access to professional supervision is often limited by practical and cultural barriers, including time constraints, competing clinical demands, resource limitations, and organisational cultures that undervalue reflective practice (Keane *et al.*, 2020; Osiurak *et al.*, 2025). Where supervision is available, its impact may be influenced by the quality of the supervisor–supervisee relationship and perceptions of the supervisor's competence (Rothwell *et al.*, 2021; O'Donnell *et al.*, 2022). For supervision to be most effective, it must be accessible and consistent, and delivered within a psychologically safe environment in which staff feel able to share vulnerabilities without fear of judgement (Martin *et al.*, 2021, 2022). In practice, this requires supervision to extend beyond clinical problem-solving to include explicit attention to the relational and emotional dimensions of care and provide space to explore issues such as professional grief, boundary challenges, and emotional distress.

Embedding effective supervision for professionals working with MND may be particularly challenging due to the rarity of the condition and the highly specialised nature of care. As a result, frontline clinicians may have limited access to managers or supervisors with direct experience of MND, potentially reducing the relevance or perceived value of available supervision. Innovative approaches may therefore be required, including discipline-specific communities of practice that incorporate supervisory elements, as well as targeted training for managers or external supervisors to support staff working in this field. Such solutions may be especially important to ensure professionals working in highly specialised or isolated roles are adequately supported in this work.

In addition, findings from the focus group study indicated that at least one participant sought external psychological support in response to the emotional impact of

working with MND. Similarly, respondents in the online survey described the benefits of access to psychological support from psychology colleagues in helping them process challenging and distressing situations. Together, these findings suggest that some professionals may require access to additional mental health or psychological supports beyond routine supervision. However, regular and structured supervision could play a key role in identifying when such additional supports are needed, while decisions regarding the availability and provision of these supports should be considered at an individual organisational level.

A summary of the recommendations aimed at fostering workplace cultures that recognise, acknowledge, and adequately respond to the practical and emotional demands placed on professionals providing care to people with MND and their families is outlined in Table 6.4.

**Table 6.4:** Recommendations to Foster Organisational Cultures that Recognise and Adequately Support the Practical and Emotional Demands of MND Patient and Family Care

**Recommendations:** Foster compassionate leadership and organisational cultures where professionals feel supported, valued and empowered to access support when needed

- **Promote autonomy and temporal flexibility** in workload management where possible
- **Promote compassionate leadership** and organisational cultures that recognise professional grief and the emotional impact of MND care, and that normalise the seeking and provision of emotional support
- **Ensure access to clinical supervision** that is appropriate to the individual needs, experience level, and professional role of clinicians working in MND care
- **Ensure access to external counselling or mental health supports** for professionals as required

## 6.3.3 The Interpersonal

This interpersonal meta-theme encompasses influences on HCPs' well-being and quality of life that arise from their day-to-day interactions within the immediate care or work environment (Penwell-Waines *et al.*, 2018). These influences are shaped through relationships with patients and their families, colleagues, and

multidisciplinary team members, and supports can include factors such as patterns of communication and the quality of peer and supervisory support (Penwell-Waines *et al.*, 2018). These micro-level dynamics play a central role in how professionals experience their work on a personal level and can mediate the impact of organisational and system level pressures through everyday encounters that either buffer stress or intensify strain (Bone, 2015).

This meta-theme explores how interactions with informal and family caregivers, as well as multidisciplinary and collegial relationships, shape HCPs' experiences of providing care for people living with MND. Across both the focus group and online survey studies, interpersonal supports were the most frequently reported sources of professional support, highlighting their central role in sustaining professional well-being. The scoping review similarly underscored the importance of multidisciplinary team working in supporting professionals involved in MND care.

## 1. Informal Caregivers - Meeting the Unique Needs of Informal Caregivers for People Living with MND

This research highlighted the pivotal role of informal caregivers in the provision of MND care. The role of MND family caregivers was identified as distinctive, due to the profound levels of everyday care typically provided by the families of plwMND. Professionals identified that witnessing how MND and the burden of care affected families was often as emotionally challenging as observing the effects of this condition on the individual themselves. To provide effective care for plwMND, participants identified how they needed to work closely with and develop trusting relationships with informal caregivers. 56% of survey respondents identified with difficulty providing care or interventions without informal caregiver support. Yet, because services are predominantly organised around the plwMND, participants in the focus group study described feelings of helplessness and emotional strain, from witnessing profound caregiver burden while lacking the resources (inclusive of time, services, skills) to meaningfully alleviate it. This sense of helplessness was echoed in the survey, where 70% identified with feeling unable to alleviate caregiver burden due

to insufficient time or services, and this was rated as the third most distressing clinical situation overall. Beyond physical demands, this research and previous studies have also highlighted the significant emotional needs, anticipatory grief (Trucco *et al.*, 2024) and psychological strain (Schischlevskij *et al.*, 2021) experienced by MND informal and family caregivers. Consistently, 55% of survey respondents identified with feeling unable to provide the emotional support or comfort required by plwMND and their families.

Managing family dynamics and the often-conflicting needs of plwMND and of their family caregivers emerged as a consistent challenge across the scoping review, qualitative study, and online survey. In the survey, 59% of respondents reported difficulties in meeting the needs of both patients and family members due to divergent priorities or opinions. These dynamics can place HCPs in ethically challenging situations in which care decisions cannot fully meet the needs of all parties involved. Clinicians are often required to navigate competing responsibilities, carefully balancing respect for patient autonomy with concerns for caregiver safety or well-being, alongside their own professional duties and obligations. The focus group findings further highlighted how the emotionally charged nature of these encounters, combined with the limitations of what professionals are often able to offer, can place additional pressure on clinicians. In some cases, this strain was experienced as a threat to previously established trust with patients and families and was internalised by professionals as a sense of personal failure or of letting patients or family members down, rather than being recognised as a consequence of systemic constraints or complex relational dynamics.

These findings underscore the need to strengthen HCPs' capacity to deliver holistic, family-centred care, enhancing their confidence and efficacy in managing family dynamics and complex situations where the optimal course of action is often unclear and emotionally charged. Supporting families of individuals affected by MND can expose professionals to feelings of helplessness, emotional strain, and moral distress, highlighting the ethical and relational complexity inherent in this work. Although the imperative to treat MND as a condition that profoundly affects the wider family is well recognised in the literature (Young *et al.*, 2023), service design and

delivery should more fully reflect the substantial time, emotional labour, specialist skills, and practical resources required to ensure that professionals are adequately equipped to meet the needs of both patients and families in practice. A summary of the supports identified across this research that may better enable healthcare professionals to address the unique needs of informal caregivers of people living with MND is outlined in Table 6.5.

**Table 6.5:** Recommendations to Enhance Professionals' Capacity to Support Informal and Family Caregivers

**Recommendations:** Enhance professional and service capacity to effectively meet the unique support needs of MND informal caregivers

- **Enhance both service and professional capacity to provide practical and emotional support for MND informal caregivers**
- **Develop MND-specific caregiver interventions**, including education, psychosocial support, and practical assistance, that reflect the progressive nature of the disease, and the increasing intensity of informal caregiving demands
- **Expand and adequately resource services such as formal home-based care support** to ensure families have access to the physical and practical assistance needed to safely and sustainably support plwMND, while also enabling professionals to offer tangible support that adequately alleviates caregiver burden

## 2. Multidisciplinary Team Communication and Collegial Relationships: Sources of Strain and Support

### Informal Peer or Collegial Support

Across both the focus group study and the online survey, collegial support emerged as a crucial factor in mitigating stress associated with clinical uncertainty, providing reassurance in complex decision-making, and offering invaluable emotional support. Informal peer interactions provided a vital outlet for sharing difficulties, uncertainties, and emotions within a safe environment of mutual understanding. These exchanges were described as fostering personal growth, reflection, and the development of new perspectives on challenging experiences. Participants in the

focus groups highlighted how positive working relationships enabled informal debriefing after difficult encounters, promoting shared understanding and reducing feelings of isolation when managing the emotional and practical demands of MND care. In the online survey, informal collegial support was identified as the most common source of support overall and was similarly identified as important in providing both practical support in complex clinical situations and emotional support for processing the challenging encounters and circumstances they were exposed to. Some respondents in this study reported that collegial support was the only form of mental health support available to them at work. Consistent with these findings, other studies have found that collegial support in challenging healthcare environments is often valued more highly than support from family or friends due to the sense of shared professional understanding (Phillips, Trainum and Thomas Hebdon, 2025).

Professionals working in community settings, who frequently visit patients and families in their homes, were identified as particularly vulnerable, as they often lacked immediate access to colleagues and, consequently, peer support, compared with those in inpatient or clinic environments. Although the survey did not quantitatively measure satisfaction with or access to collegial support, its potential influence on professional quality of life warrants further investigation. Future work should also explore how organisations can best facilitate informal peer and collegial support for all professionals working with plwMND, especially for lone workers. Potential strategies include peer "*buddy*" systems and structured remote support models that offer regular check-ins and on-demand contact with a trusted colleague (Schrøder *et al.*, 2022; Wilkinson, Ajjawi and Mansouri, 2024). Evidence suggests that allowing staff to self-select peers enhances trust, which is a crucial condition for effective peer support (Schrøder *et al.*, 2022). However, for such support to be meaningful and sustainable, it must be embedded into routine practice, with protected time and a workplace culture that recognises collegial connection as integral to compassionate and sustainable care. One focus group participant reflected feeling that they were "*not actually working*" when debriefing with colleagues, despite recognising these conversations as essential for processing the

difficult encounters they were exposed to. This highlights how workplace cultures may undervalue such interactions, even though evidence shows that peer support can enhance professional well-being, strengthen professional relationships, and reduce burnout (Agarwal, Brooks and Greenberg, 2020; Hussan *et al.*, 2024; Collett, Emad and Gupta, 2025). This is also an accessible intervention that can be implemented with minimal resources (Rivera-Chiauzzi *et al.*, 2022).

### The Multidisciplinary Team

Each phase of this research identified being part of a supportive and well-functioning MDT as a critical enabler for managing the complex challenges of caring for plwMND. The scoping review highlighted the importance of effective MDT working and strong professional relationships, with 41% of sources describing these as essential for delivering high-quality care and enhancing job satisfaction. Focus group participants echoed this, emphasising that collaboration within the MDT helped to alleviate the anxieties, dilemmas, and uncertainties inherent in care planning and decision-making. Stress related to clinical uncertainty was mitigated when team members engaged in shared decision-making and interdisciplinary problem-solving. Survey findings identified working within a supportive MDT as the second most helpful form of support. Additionally, 21 respondents described the multidisciplinary nature of their work as central to their ability to remain working in the field, underscoring the importance of collaborative care planning and decision-making.

By contrast, both the scoping review and focus groups revealed that professionals who lacked MDT support frequently reported feeling overwhelmed, vulnerable, and isolated. Some survey respondents also indicated that the absence of effective team support contributed to their consideration of leaving their roles. Focus group discussions suggested that professionals working in inpatient or clinic-based settings generally had more positive experiences of team communication and collaboration, facilitated by regular meetings and established communication

structures. In comparison, those working in community or residential care settings faced greater challenges due to dispersed teams, limited access to the full range of MDT members, and fewer structured opportunities for whole team interaction. While the value of MDT structures is well documented and recommended within specialist MND services (Motor Neurone Disease Association, 2022), findings from the scoping review and focus group studies highlighted the need for consistent and effective MDT support across all services involved in the care of plwMND, as well as stronger collaboration between external teams and service providers (addressed in Section 6.3.1). Collectively, these findings highlight the critical importance of structured, accessible, and well-supported MDT collaboration and communication within all care settings, not only within specialist centres, to meet the complex needs of plwMND and their families, while also reducing professional stress, anxiety and isolation among those providing their care.

In addition to the importance of robust MDT structures and interdisciplinary collaboration in managing the stress and anxieties associated with care planning and delivery, having strong, trusting, and supportive relationships within these teams was identified as equally vital for managing the emotional demands of MND care. This emphasis on relational cohesion is also reflected in the MNDA UK guidance on Multidisciplinary Team Working for MND (Motor Neurone Disease Association, 2022). In the focus group study, many professionals described how working alongside colleagues in challenging circumstances fostered a sense of connection and mutual understanding. However, others observed that, in the absence of effective leadership, open communication, and mutual support, the pressures of providing MND care could generate tension and strain team dynamics. The importance of team cohesion was especially emphasised when managing complex cases and particularly when caring for patients with cognitive or behavioural changes. Across all phases of the research, professionals highlighted the value of being able to rely on colleagues for guidance and emotional support, noting that humour and informal relationships within teams often played a crucial role in alleviating the emotional weight of this work.

### Formal Team-Based Interventions

Although formal team interventions such as reflective or debriefing sessions were seen to be of value in both the focus groups and online survey, most reported that such support was not routinely embedded in practice and was often deprioritised by teams or organisations. Access to structured, team-based emotional support was described exclusively by those working in specialist palliative care settings in the focus group study. Previous studies have found that professionals who do not work in palliative care services and lack specific training in end-of-life care, are often more adversely affected by patient deaths, due to reduced preparedness and a reduced sense of meaning and efficacy when supporting patients at the end of life (Magee, Lusher, and Provost's Group, Regent's University London, London, UK, 2023; Werrett, McIlveen and Fox, 2025). In this research these professionals were also those who were less likely to receive support in processing these challenging experiences and encounters with often complicated deaths.

Structured interventions, such as Schwartz Rounds, Balint groups, debriefing sessions, and reflective practice forums are interventions that provide safe, confidential spaces for professionals to process the emotional demands of healthcare work (Scott, O'Curry and Mastroyannopoulou, 2022; Neil *et al.*, 2023; Ng *et al.*, 2023). While using these forums to reflect on individual and shared challenges has been shown to create a sense of camaraderie and reduce feelings of isolation (Taylor *et al.*, 2018), an added benefit of these interventions is the opportunity to share positive stories of impact, which can reinforce the meaningful nature of the work often helping to sustain motivation and resilience. These approaches have shown effectiveness in other complex clinical areas but remain underexplored in the context of working specifically with MND or other progressive neurological conditions (Maben *et al.*, 2021; Scott, O'Curry and Mastroyannopoulou, 2022; Neil *et al.*, 2023; Ng *et al.*, 2023). Therefore, the efficacy of these more formal approaches to interpersonal support for those delivering MND care should be considered in future research. Moreover, consideration should be given to delivering these interventions across services, particularly following especially challenging cases, where multiple teams and services were involved in supporting patients and families. MND charity organisations may be well positioned to help co-ordinate and extend such supports,

to ensure they are accessible not only to those working in specialist teams but also to professionals who engage with plwMND less frequently yet still require opportunities for emotional and professional support.

In recent years, several team-based interventions have also been developed to address moral distress among HCPs in high-stress settings such as critical care and oncology. Approaches include reflective debriefing (Browning and Cruz, 2018), facilitated ethics conversations (Wocial *et al.*, 2024), ethics communication groups (Margareta, Ulf and C., 2025), and interdisciplinary case conferences (Devireddy *et al.*, 2025). These interventions provide structured opportunities for staff to process and learn from ethically challenging situations collectively. Given the instances of moral distress described and identified in this research such team-based interventions also warrant consideration in the context of healthcare teams supporting individuals and families living with MND.

A summary of the recommendations developed from the integrated findings relating to multidisciplinary communication, team support, and professional relationships, identified as essential to effective and safe MND care delivery, is presented in Table 6.6 below.

**Table 6.6:** Recommendations to Improve Access to Multidisciplinary Team Working and Collegial Support for All Healthcare Professionals Providing MND Patient Care

**Recommendations:** All professionals working with patients and families living with MND should have access to both formal and informal interpersonal and multidisciplinary team supports

- **Strengthen collaborative multidisciplinary practice** by establishing routine whole team communication structures across all care settings
- **Formalise and resource peer support mechanisms** ensuring staff have consistent access to collegial or peer support, particularly for lone workers
- **Invest in team development** training and initiatives designed to build trust, enhance collaboration and promote psychological safety within teams
- **Provide structured opportunities for team reflection and debriefing**
- **Explore the benefits of interdisciplinary team-based interventions** in reducing the impact of moral distress

### 6.3.4 The Individual

The individual-level meta-theme encompasses influences on HCPs' well-being and quality of life that arise from the personal characteristics, professional capabilities, and individual resources that clinicians bring to their work (Penwell-Waines *et al.*, 2018). Individual-level factors can play a critical role in determining how professionals experience stress or meaning and fulfilment in their roles, and interact with interpersonal, organisational, and system-level conditions to either heighten vulnerability or strengthen adaptive capacity in challenging clinical contexts. (Penwell-Waines *et al.*, 2018).

This individual-level meta-theme presents influences identified throughout this research that shape clinicians' experiences of working with the complexities of MND care and their impact on individual well-being. It encompasses potential professional risk and protective factors, as well as clinical knowledge and skills that enhance perceived confidence and effectiveness in practice, alongside personal resources and attributes, such as psychological dispositions, coping styles, and resilience, that further shape how individuals experience and sustain their work in this challenging field.

#### 1. Risk and Protective Factors Influencing Professional Well-Being in MND Care

##### Age and experience

The scoping review showed inconsistent findings regarding the effect of clinical experience on professional's experiences of delivering MND patient care, and age was not identified as a factor in this study. Prior experience was sometimes helpful (Olesen *et al.*, 2022), but not consistently so; in some cases, more years of experience were linked to higher stress (Bromberg, Schenkenberg and Brownell, 2011).

Age and experience were both identified in the focus group study as influential in shaping the emotional impact of working with people living with MND. Many

professionals reflected on their early experiences, describing how they were initially deeply affected by the condition of the patient and family distress and experienced significant uncertainty in relation to the provision of effective clinical care. Over time they developed strategies that helped them to manage emotionally charged interactions, navigate boundaries, manage uncertainty, and better cope with the emotional weight and clinical complexity of the work. Participants noted how new team members often struggled with the practical and emotional demands of MND care and emphasised the need for additional support for those less experienced. This finding aligns with evidence that novice HCPs often feel underprepared for patient loss and death, rendering them more vulnerable to the emotional impact of such experiences (Phillips, Trainum and Thomas Hebdon, 2025). While Zybarth, Inhestern and Bergelt (2025) suggest that regular engagement with patients affected by rare diseases may have a protective effect, as the accumulation of knowledge and expertise enhances professional confidence, strengthens engagement, and fosters a deeper sense of meaning and connection to one's work.

The survey data supported several of these findings. Younger professionals reported lower compassion satisfaction and reduced coping resilience, possibly due to greater uncertainty and a reduced sense of efficacy in managing patient deterioration, complex symptom needs, and ethical uncertainty. In contrast, those with more years of experience working with MND, reporting higher levels of compassion satisfaction, however, they also reported higher levels of burnout, likely reflecting the cumulative emotional and ethical toll of this demanding work.

These findings, indicate that professionals are likely require different supports at different stages of their careers. Effective onboarding, induction and mentoring programmes that ensure new staff have access to adequate education, training and collegial support systems, may help to reduce initial feelings of uncertainty, moral distress and secondary trauma, as was suggested by focus group participants. While, ensuring services are adequately resourced, with strong team-working structures and supportive organisational cultures, may help experienced professionals to manage cumulative emotional demands, distribute workload effectively, prevent burnout over time, and support career longevity.

### Extent And Duration of Professionals' Exposure to People Living with MND and Their Families

The focus group study suggested that a more varied caseload or shorter periods of continuous exposure to plwMND may offer some protection against emotional strain for certain professionals. However, the quantitative data did not support this assumption. The proportion of the working week spent with MND patients showed only a weak association with professional well-being measures and did not significantly contribute to any multivariable models. Likewise, no significant differences were observed on well-being outcomes between full-time and part-time staff. Although nurses had the highest levels of exposure to plwMND, they demonstrated significantly lower levels of burnout and secondary traumatic stress, which may reflect the protective effects of continuity in care and the opportunity to develop trusting and collaborative relationships with patients and families, as identified in the focus group study as key determinants of job satisfaction.

Overall, while this research did not find that higher levels of exposure to MND care negatively impacted professional well-being, qualitative findings highlighted the importance of how exposure is managed. In particular, temporal flexibility and autonomy in caseload management emerged as critical factors enabling professionals to balance workload, emotional demands, and patient needs in line with individual capacity. As discussed in greater depth in Section 6.3.2, these organisational conditions appear to support professionals in managing high levels of exposure to challenging cases and should be carefully considered for those working with this patient population.

### Gender

In the bivariate analyses, females reported significantly higher levels of moral distress and secondary traumatic stress than males. However, these differences were not significant in multivariable analyses and were not highlighted in qualitative findings, suggesting that the observed effect may have been influenced by the higher proportion of females in the sample. Previous studies reporting gender differences in moral distress and professional quality of life also caution that such findings may reflect gendered differences in emotional labour, cultural norms surrounding

emotional expression, and varying willingness to disclose distress, rather than true differences in prevalence (Lamiani, Borghi and Argentero, 2017). These findings suggest that gender-related differences in professional well-being among those working in MND care warrant further consideration.

### Profession

In the focus group study, several professionals noted that the intensive and frequent care provided by nursing and care staff, particularly in inpatient settings, could be especially burdensome and increase the risk of burnout. Interestingly, the quantitative data suggested that nurses, despite their higher exposure to MND patient care, appeared better able to manage the emotional and psychological demands of this work, experiencing lower levels of both burnout and secondary traumatic stress compared with other professional groups. This coping capacity may be related to their perceived efficacy in providing ongoing care despite the uncontrollable nature of disease progression or to aspects of their professional training. It is also important to note that nurses in the online survey were recruited from MND-specific organisations, likely reflecting a group who either self-selected to work in this clinical area or were experienced in working with this patient population. In contrast, many focus group participants were professionals with less experience and recruited from community and regional care services.

The online survey also revealed that recognition of moral distress varied across professional groups, with higher levels reported by AHPs (75%) and nurses (70%) compared with medics (56%). Variation was also observed in both the clinical scenarios most frequently encountered and those perceived as most distressing across professional groups. For example, nurses reported greater difficulty in providing adequate emotional support than medics and AHPs. Medics more frequently identified challenges in ensuring optimal symptom management than nurses and AHPs, while AHPs reported greater difficulty engaging in future care planning conversations compared with nurses and medics.

These findings highlight that the sources and manifestations of moral distress, clinical challenges, and threats to professional well-being in MND care can differ

meaningfully across professional groups. This underscores the need for profession specific understanding of their experiences and the development of targeted strategies that reflect the distinct roles, responsibilities, and pressures faced by different disciplines.

A summary of recommendations identified from the analysis of individual professional risk and protective factors across all phases of this research is presented in Table 6.7 These findings may support leaders, managers, and individual clinicians in identifying targeted support requirements.

**Table 6.7:** Recognising and Supporting Individual Professional Risk Factors

| **Recommendations:** Recognise and provide individualised support to those who might be at increased risk of emotional or psychological strain when working with MND<br><br>• **Design and implement effective onboarding and induction programmes** with regular access to senior or peer mentor support for those new to working with this population<br>• **Identify profession-specific sources of moral distress and clinical challenges** and implement targeted support strategies tailored to the needs of different professional groups working in MND care |
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## 2. Clinical Knowledge, Skills, and Professional Development: Enhancing Professional Confidence and Competence in MND Care

As is common with rare diseases (Tumiene *et al.*, 2022), knowledge gaps were frequently identified in the focus group study as a source of anticipatory stress, uncertainty, and helplessness, particularly among professionals who encountered MND infrequently or were relatively new to working with this patient population. Across all phases of this research, both explicit and implicit education, training, and development needs were identified for professionals working with plwMND, across specialist, regional and community-based settings (Table 6.9). In the focus group study those in community and regional roles, described opportunities to connect

with colleagues in specialist services as highly valuable. Meanwhile, professionals within specialist MND services stressed the importance of raising awareness and building confidence in MND care across non-specialist settings but noted that their ability to deliver such training was typically limited by workload pressures, time constraints, and the need to prioritise direct patient care.

Across all phases of this research, the need for specialist knowledge and skills was consistently highlighted. Many professionals reported that their confidence and expertise in working with this condition developed primarily through hands-on experience and informal learning from senior colleagues, often in the absence of structured or regular training opportunities. This was evident among professionals working in both specialist and non-specialist MND services, who described how increased exposure to plwMND and mentorship from more experienced colleagues played a key role in building their competence and confidence. To strengthen the specialist MND workforce required to deliver high-quality care and support colleagues in non-specialist services, more formalised education and training pathways could be beneficial. Reflecting this, a UK study recently recommended the development of a dedicated postgraduate-level course in MND care to advance specialist expertise (Chau *et al.*, 2025). Findings from the present research further suggest that formal training and clear guidelines in the provision of neuropalliative care could play a critical role in addressing many of the knowledge and skill gaps identified.

Professionals across all services in the focus group study also highlighted that the unique challenges of MND, together with the high level of interdisciplinary collaboration required, creates valuable opportunities for professional learning and development. Open-text responses from the online survey further identified professional development and growth as a key benefit of working with this patient population. Survey respondents who most strongly agreed that they could "*grow in positive ways by dealing with difficult situations"* also reported higher levels of compassion satisfaction, highlighting the value of learning and development gained through experiential learning or managing the challenges associated with MND care. Accordingly, ensuring structured opportunities for experiential learning, such as

supported exposure to complex cases, reflective practice, and mentorship may not only enhance clinicians' confidence and competence in delivering care to patients and families, but also reinforce their sense of purpose and impact in this challenging field.

Professionals in this research expressed strong motivation and willingness to engage in training and development opportunities, seeking to enhance their confidence and competence in caring for patients with this rare and heterogeneous condition. However, to address the identified gaps in knowledge and professional development, training and educational resources need to be up to date, consistently available, and readily accessible to clinicians at the point of need. Many National and International ALS/MND organisations, including the International Alliance for ALS/MND, EUpALS, the Irish Motor Neurone Disease Association (IMNDA) and the Motor Neurone Disease Association (MNDA, UK), already provide valuable resources such as webinars and educational materials. However, resources are dispersed across platforms and do not fully address the broad range of needs that were identified through this research. These voluntary organisations play a vital role in providing information and support for patients, families, and HCPs, however, establishing a centralised and unified platform for educational content, both within and across these organisations, could improve access, reduce duplication, and strengthen professional learning across all care settings. Such a resource would also help ensure that patients and families receive consistent, accurate, and up-to-date information, thereby enhancing credibility and minimising the risk of receiving conflicting messages and information from multiple healthcare providers. A useful example of this model is the International Cystic Fibrosis Training Network (ICFTN), a global initiative developed to support HCPs in delivering high-quality, multidisciplinary care to individuals with cystic fibrosis. Funded by the Cystic Fibrosis Foundation, ICFTN offers structured virtual training sessions, mentorship opportunities, and a broad range of educational resources. Its aim is to build clinical capacity and improve standards of care, particularly in settings with limited access to specialist expertise, by connecting clinicians to experienced teams and providing practical, evidence-based learning tools.

In addition to practical training needs related to managing specific aspects of MND care, such as addressing cognitive and behavioural changes or supporting the use of aids, devices, and technologies, this research identified a number of core professional skills and attributes, equally important for professional development. These skills can not only support professionals working with plwMND but are also likely transferable to the care of people with other rare, complex, and progressive conditions, making investment in such education broadly valuable across the healthcare system. The National Rare Disease Strategy (2025), recently published in Ireland, reinforces this need by calling for rare disease education to be embedded at all levels of healthcare education, from undergraduate to postgraduate and continuing professional development. Key areas include approaches to patient and family centred care, advanced communication skills, strategies for managing uncertainty in practice, and training to strengthen emotional capacity and professional well-being.

In addition to this, educational interventions that incorporate ethics training, communication skills development, and reflective practice represent some of the most common and promising approaches to addressing moral distress (Molazem *et al.*, 2013; Monteverde, 2016; Meziane, Ramirez-Garcia and Fortin, 2018; Abbasi *et al.*, 2019). However, these programs vary widely in their theoretical underpinnings, content, and duration, which limits replication and comparability of outcomes (Morley *et al.*, 2021). Targeted education focused on recognising and managing ethical tensions specific to MND care should however be considered. Education should also focus on differentiating between different aspects of healthcare professional quality of life and providing professionals with the knowledge to recognise signs of burnout, compassion fatigue and moral distress, and hence the ability to apply coping strategies effectively. As was identified in this research, more professionals identified with the experience of moral distress than had previously heard of the concept, highlighting a significant gap in awareness and education.

Research participants valued being involved in and updated on advancements in the field of MND research. Given the many uncertainties surrounding MND, there appears to be a strong interest among HCPs in research, seeking to uncover causes,

identify effective treatment options, and improve care and quality of life. Engagement in research may serve as a protective factor against the helplessness some professionals experience, by offering a renewed sense of agency and purpose, that they are contributing to advancing knowledge and improving patient and family experiences of living with the condition. Involvement in research may also provide valuable opportunities for professional development and fulfilment. Creating structured opportunities for clinicians to engage in research initiatives as part of their clinical roles could therefore be an important strategy for workforce sustainability, while simultaneously enhancing the quality of MND care. A commitment to life-long learning and development is also potentially an important attribute for those working in this area and with a condition where new knowledge, guidelines and innovations are continuously emerging.

Future research should consider the effectiveness of different training interventions and modalities of training in enhancing HCP competence and confidence in working with the MND population, both in regional and community and in specialist services. While it was not a question that we asked in this study, several education and training gaps were identified both from participants themselves and from the analysis of study results, while further research on identifying the training priorities for professionals working in both MND specific and non-specific services would be beneficial, some suggestions from this research are outlined in Table 6.9 below. Table 6.8 further summarises recommendations identified across this research to support healthcare professionals in accessing the clinical knowledge, skills, and education required to confidently deliver effective, person-centred, and holistic MND care.

**Table 6.8:** Recommendations to Equip Healthcare Professionals with the Clinical Knowledge and Skills to Confidently Provide MND Patient and Family Care

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|---|
| **Recommendations:** Create opportunities for frequent and accessible education, training and development for professionals at all levels of experience of working with people and families living with MND.<br>• **Integrate core training on rare, uncommon, and less well-known conditions** into undergraduate healthcare curricula to build foundational skills for working with these patient populations |

- **Develop postgraduate programmes and short courses (micro-credentials)** focused on the specific challenges of caring for people with MND, to strengthen workforce knowledge, skills, and confidence in this complex area of practice
- **Provide regular, accessible, and up-to-date educational and training resources,** including workshops, webinars, and discipline-specific training, to support ongoing professional development in MND care. See Table 6.9 below for some of the education, training and development needs and gaps identified through this research.
- **Strengthen the capacity of MND specialists** to design, update, and deliver educational opportunities for professionals working in community and regional services
- **Consider opportunities for experiential learning,** such as facilitated exposure to complex cases, mentorship from experienced clinicians, and regular reflective practice and case-based discission sessions within MDTs
- **Establish a centralised educational hub** within MND charities and voluntary organisations, offering up-to-date resources, recorded webinars, and information on training and events, maintained regularly and promoted widely among community and regional care teams
- **Create clinical–research posts** to address current knowledge gaps, improve care processes and quality of life for patients and families, and provide professionals with opportunities for career development and engagement
- **Consider the development of discipline-specific, international communities of practice for MND specialists** to foster knowledge exchange, and provide ongoing opportunities for learning, supervision support, collaboration, professional development and education
- **Undertake future research** to evaluate the effectiveness of community-based training, networking events, and educational opportunities in improving the knowledge and confidence of community and regional providers, and to identify the most effective modes of delivery

**Table 6.9:** Education, Training, and Professional Development Needs Identified Through This Research

- **Education and training on aids, devices, and assistive technologies** commonly used by people living with MND, including practical guidance on their application and day-to-day use
- **Training in recognising and managing cognitive and behavioural changes** associated with MND, incorporating strategies to support affected individuals and address the impact of these changes on team dynamics and interpersonal relationships in care settings
- **Advanced communication skills** tailored to MND care, focusing on communicating uncertainty, managing emotionally difficult conversations, reframing hope and meaning in the context of a progressive illness, and effectively communicating with patients who have speech or communication impairments

- **Psychological support training** to equip professionals with the skills to respond to the emotional and existential distress experienced by patients and families, including how to be present and hold space for emotional distress and manage their own emotions in these complex interactions
- **Education and guidance on applying a neuropalliative care and rehabilitative approach**, including principles and strategies for optimising comfort, autonomy, function, and quality of life in the context of a progressive, life-limiting neurological condition
- **Professional well-being training**, supporting professionals to recognise and identify signs of moral distress, compassion fatigue and burnout, and how to implement appropriate strategies to mitigate the type of emotional strain experienced

## 3. Individual Professional Skills, Resources, and Attributes: Supporting Sustained Engagement and Well-Being in MND Care

One of the objectives of this research was to identify professional characteristics, resources, and coping mechanisms that may support HCPs to remain working amidst the challenges associated with providing MND patient care. A number of such characteristics, skills, attributes, and coping processes identified in this research are explored in greater depth below.

### Adaptability and Cognitive Flexibility

The ability to adapt one's thinking, decision-making, and behaviour in response to changing patient needs was identified as a key skill for delivering effective person-centred care for plwMND and their families. In the focus group study, participants identified flexibility, adaptability, problem-solving, perspective-taking, and a solution-focused mindset as essential attributes when working with this cohort. This reflects the reality that patient needs and preferences evolve over time, requiring clinicians to respond to shifting priorities often while managing significant clinical uncertainty, practical challenges, and frequent ethical dilemmas. Although advance care planning and preparation for anticipated changes were recognised as important, professionals emphasised that many situations could not be fully predicted or

planned for, and therefore required responsive, adaptive approaches as issues arose. This perspective was reinforced by findings from the online survey, where 51% of respondents reported difficulties planning future care due to uncertainty in the trajectory of disease progression. As discussed at length in Chapter Four the capacity to tolerate uncertainty was proposed as a potential protective factor that may help clinicians navigate the evolving, ambiguous, and ethically complex nature of MND care.

Cognitive flexibility is another skill that relates to the ability to adapt one's thinking and behaviour in response to changing circumstances (Goldin, Alvarez and Von Harscher, 2025). It involves two broad concepts, the first is *cognitive control*, which is the confidence to perceive difficult situations as controllable and the second is *cognitive alternatives*, which is the ability to identify multiple solutions to a problem (Dennis and Vander Wal, 2010). Therefore, cognitive flexibility, enables HCPs to adapt to rapidly changing conditions, quickly analyse complex problems, generate alternative thoughts and ideas and cope effectively with new and difficult situations (Ayal, 2023; Goldin, Alvarez and Von Harscher, 2025). Evidence from recent research shows that greater cognitive flexibility is linked to higher tolerance of uncertainty, meaning that those who can adapt their thinking effectively are more comfortable navigating ambiguous situations (Demirtas, 2020; Godara *et al.*, 2023; Inozu *et al.*, 2023). In the context of working with plwMND, cognitive flexibility is likely to be highly beneficial in enabling professionals to adapt to the diverse challenges identified though this research. These include responding effectively to rapidly changing clinical situations and unforeseen challenges, tailoring care to the evolving priorities and needs of patients and families and maintaining confidence in their ability to manage unanticipated circumstances as they arise.

This research highlights the vital importance of individualised, person-centred care in MND, which requires professionals to tailor their approach to each patient's values, goals, and preferences, and, as discussed in Chapter Four at times requires a willingness to support people with decisions or choices may be perceived as unwise or risky. Delivering such care involves substantial practical and emotional labour, including building trusting relationships, developing personalised care plans,

and balancing competing demands such as resource constraints, service access, family perspectives, patient values, psychological well-being, and the realities of disease progression. Professionals must also recognise that patient and family priorities evolve over time, necessitating flexibility within both current and future care planning while maintaining a focus on personhood and dignity (Aoun *et al.*, 2018; Harris, Jack and Wibberley, 2023). In this context, cognitive flexibility may play a crucial role. Beyond helping professionals to manage high levels of uncertainty and shifting caseloads, it may enable them to tailor interventions to individual patients, incorporate patient and family preferences into care planning, and respond effectively when standard protocols do not fully meet patients' needs. By supporting both the practical and relational dimensions of care, cognitive flexibility is a skill that may support clinicians to remain adaptable, open to alternative perspectives, and effective in conditions of uncertainty when working in these complex and dynamic care environments.

Correlational studies have identified mindfulness as a significant predictor of both cognitive flexibility and reduced perceived stress (Aydın Sünbül, 2020; Aiman Aftab, Syeda Mahrukh Waqar and Ayesha Yashfeen, 2025). Similarly, Acikgoz and Karaca (2025) reported that a mindfulness-based cognitive therapy program produced positive effects on cognitive flexibility, as well as reductions in anxiety and depression among nursing students. Emerging evidence also suggests that mindfulness-based interventions, including Mindfulness-Based Stress Reduction (MBSR), can benefit professionals working in palliative and end-of-life care (Covington *et al.*, 2023; Kaur, Sharma and Chaturvedi, 2023), as well as other healthcare settings (Kriakous *et al.*, 2021). Mindfulness practices and interventions were further identified as beneficial, in this research, by respondents to the online survey. To date, however, research has largely focused on the impact of these interventions on general psychological well-being. Their potential to strengthen professionals' capacity to remain present, engaged, and resilient when navigating complex, uncertain, and rapidly evolving clinical situations, without becoming overwhelmed or avoidant, represents an important and underexplored direction for future investigation.

### Emotional Capacity

This research identified how HCPs working with plwMND and their families are frequently exposed to intense emotional experiences related broadly to the diagnosis, disease progression, death, and grief.

In the scoping review difficult conversations around delivery of the diagnosis, disease progression and future or end of life care planning were identified as having an emotional impact on the professionals responsible for these discussions. The focus group study expanded on this and professional skills and competence in emotional self-awareness, regulation, and processing were identified as essential in managing these difficult encounters. Professionals frequently spoke of managing the raw emotions of patients and families, which at times left them feeling helpless in their ability to ease the profound, non-physical suffering they witnessed. Many described connecting with patients and families on a deeply human level, which was both enriching, due to the depth of connection, and challenging, given the emotional toll it carried. While being present and holding space for patients and families to express profound loss and sadness was seen as a vital aspect of the role, the emotional intensity of these interactions often weighed heavily on the professional. Many identified instances of becoming emotional or tearful themselves in these interactions.

While some participants reported that repeated exposure to these interactions helped them develop emotional boundaries and strategies to manage both their own and the emotions of others, they acknowledged that these encounters could still leave a lasting impact, particularly when close therapeutic relationships or connections had been formed. The online survey echoed these findings, with 55% of respondents reporting difficulty in providing the level of emotional support they felt patients and families required. The cumulative impact of working continuously with loss, sadness, and grief emerged as the most frequently cited reason for considering a role change within MND services or needing a period of time away from work. These findings highlight the significant emotional demands placed on professionals, the challenges involved in managing emotionally charged encounters and the cumulative emotional weight of this work.

Skills aligned with emotional intelligence, defined as the capacity to recognise, understand, and manage one's own emotions while responding appropriately to the emotions of others (Bru-Luna *et al.*, 2021), were repeatedly described as important for navigating these encounters by focus group participants. Research has shown that professionals with higher emotional intelligence are better able to manage the demands of emotional labour and report lower levels of burnout and professional distress (Chen, Huang and Chu, 2024; Stoian-Bălăşoiu *et al.*, 2025). Consistent with this, in the present study, survey respondents who strongly agreed with the BRCS item *"Regardless of what happens to me, I believe I can control my reaction to it",* reported significantly lower levels of secondary traumatic stress, suggesting that perceived competence in emotional regulation may serve as a protective factor against professional distress in this context.

Focus group participants also emphasised the importance of emotional self-awareness, recognising personal limits and knowing when to seek support from colleagues or external sources. While some described using emotional distancing as a coping strategy, there is evidence to suggest that excessive emotional suppression can increase the risk of burnout and compassion fatigue over time, however an element of emotional distance is often required and beneficial to be able to effectively fulfil professional duties (Merlo *et al.*, 2020; Yang and Chen, 2021). As with empathy, participants consistently identified empathy as a core professional skill and an essential resource for building trust and forming effective relationships in MND care. However, research suggests that clinicians with high levels of empathy may also be at increased risk of psychological distress when they lack sufficient emotional regulation skills (Duarte, Pinto-Gouveia and Cruz, 2016; Hunt, Denieffe and Gooney, 2017; Watson *et al.*, 2025).

Psychological flexibility is generating increasing interest in research on HCP well-being and psychological functioning (Duarte and Pinto-Gouveia, 2017; Kent, Hochard and Hulbert-Williams, 2019; Holmberg *et al.*, 2020; Ortiz-Fune, Kanter and Arias, 2020; Garner and Golijani-Moghaddam, 2021). Psychological flexibility is described as *"the ability to contact the present moment more fully as a conscious human being, and to change or persist in behaviour when doing so serves valued*

*ends*" (Hayes *et al.*, 2006, p.7). Importantly, psychological flexibility is the ability to do this despite experiencing distressing or challenging internal experiences, such as thoughts, emotions, physiological sensations, memories, or images (Hayes *et al.*, 2006). This conceptualisation aligns with descriptions offered by professionals in the focus group study, who described their ability to '*sit with distress'*, rather than becoming overwhelmed or avoidant, and to regulate their own emotions to remain consistent in their role whether offering appropriate comfort and support, or to just sit with and validate the emotion being expressed.

A systematic review and meta-analysis by Garner and Golijani-Moghaddam (2021) found that HCPs who report higher levels of psychological flexibility also report lower levels of compassion fatigue and higher levels of compassion satisfaction. As such, it is likely that targeting psychological flexibility may be valuable in promoting work-related quality of life for HCPs. While emotional intelligence and psychological flexibility are distinct, as emotional intelligence helps people to understand and manage emotions, while psychological flexibility helps them to remain open, present and values driven in emotionally difficult situations. Evidence suggests that psychological flexibility can strengthen or mediate the benefits of emotional intelligence for professional well-being (Toghraie Semiromi *et al.*, 2023).

Psychological flexibility is increasingly recognised as a malleable capacity that can be deliberately strengthened, and it forms a central target of contemporary third-wave cognitive behavioural interventions, most notably Acceptance and Commitment Therapy (ACT) (Hayes, 2004; Hayes *et al.*, 2006, 2013). Related approaches, including mindfulness-based stress reduction and cognitive reappraisal strategies, have also demonstrated effectiveness in enhancing HCPs' emotional regulation skills and overall professional quality of life (Lamothe et al., 2016; Măirean, 2016; Ducar et al., 2020; Cascales-Pérez et al., 2021; Wobeto et al., 2022). These interventions highlight the potential for developing adaptive psychological capacities that could better support clinicians in managing the emotional and cognitive demands of these complex interactions and conversations. Although some individuals may possess a natural aptitude for emotional intelligence and regulation, growing evidence indicates that these skills can be systematically cultivated (Powell

*et al.*, 2024; Salem, Hashimi and El-Ashry, 2025). As suggested by participants in this research, in addition to formal psychological interventions, structured opportunities for reflection and emotional processing, such as supervision, debriefing, and peer support, may also play a crucial role in enabling clinicians to acknowledge, learn and grow from some of the challenging encounters and experiences they are exposed to.

Accordingly, future research should prioritise the evaluation of interventions designed to enhance HCPs' emotional awareness, psychological flexibility, and regulatory capacity and evaluate the impact on both confidence in managing emotionally charged interactions and the consequent impact on professional quality of life.

### Transcendental Meaning-Making

An important finding from this research was that working with plwMND can offer profound benefits for professional well-being. Many employees are drawn to end-of-life care because of the intrinsic rewards of this work, such as the satisfaction of helping others, forming meaningful relationships, and witnessing the tangible impact of their efforts (Moreno-Milan *et al.*, 2019; Zapf *et al.*, 2021). This aligns closely with the findings of this research, which found that the primary motivations for continuing to work in this field were deeply intrinsic and rooted in the job satisfaction of making a meaningful difference in the lives of others and knowing that they were offering help and support at a time when patients and families needed it most. The survey findings further supported this, showing that despite recognising moral distress and the challenges inherent in this work, the vast majority of participants expressed a clear intention to continue working in MND in the future. Overall, these findings indicate that professionals derive a profound sense of meaning from their work with this population, which acts as a vital sustaining factor supporting their continued commitment and engagement.

One way through which professionals cultivated a sense of meaning and purpose, as revealed in the focus group study, was through both the identification and communication of sources of hope and positivity. This helped them reframe both

patients' and families' feelings of hopelessness, as well as their own sense of helplessness in the face of MND's relentlessly progressive nature. The perceived inability to help was identified as a key driver of professional distress in this research. However, by actively reflecting on the difference they could make, through being present, providing information and support, and recognising how even small interventions could significantly enhance the quality of life of plwMND and their families, professionals were able to reframe their sense of purpose and professional effectiveness. This process involved deliberately shifting focus from what was beyond their control to what they could meaningfully contribute, reflecting the approach they used with patients and families, emphasising what the person could still do rather than dwelling on losses or what was no longer possible.

This recognition of their impact, combined with an acceptance of personal and wider service or system level limitations, also emerged in the online survey as the professional attribute most frequently identified as supportive in this work. Respondents described how focusing on aspects of care they could influence, rather than on factors beyond their control or the inevitability of decline, helped them to find meaning in their role and a sense of purpose in supporting individuals and families affected by MND. The high proportion of professionals who reported both high levels of compassion satisfaction and professional fulfilment in the online survey is likely influenced by the fact that these research participants were recruited from MND services, where clinicians typically possess advanced skills and a deep awareness of the value of their contribution to this field. Similar observations were made in the focus group study for those working in specialist MND roles.

An important consideration arising from this research is how best to support professionals who encounter MND less frequently, particularly in helping them to find meaning in this work and to recognise the value of consistent rehabilitative and supportive interventions, even in the context of progressive clinical deterioration. As discussed in Chapter 4 accessible education on applying a neuropalliative care approach is likely central to this effort. Equally important is fostering a culture of interprofessional support within organisations, where staff can reflect on the positive impact of their work, learn from challenging encounters, and actively share affirming

feedback received from colleagues and families. Receiving expressions of gratitude from patients has been shown to enhance occupational self-efficacy, perceived social worth, and overall workplace well-being (Li *et al.*, 2025) and was similarly identified as a rewarding aspect of the work in this research. Together, these practices may help more professionals engage in meaningful sense-making, shifting perspectives from feelings of futility to fulfilment and reducing experiences of helplessness when caring for individuals facing inevitable terminal and progressive decline.

### Resilience

A particularly interesting and novel finding from this research was the identification of another distinct process through which professionals derived meaning and purpose from their roles. This process involves accounts of vicarious resilience, which served as a source of strength, personal growth, and affirmation of the significance of their work. The unique contribution of vicarious resilience lies in witnessing others overcome adversity, a process that appears to transform how professionals perceive the value and purpose of their roles. This is discussed at length in Chapter Four. A small number of survey respondents also elicited this form of resilience, through perspective taking, and reflection, on how fortunate they felt to have their health compared to the profound difficulties faced by the individuals and families in their care.

In the online survey, the Brief Resilient Coping Scale (BRCS) was used to measure resilient coping due to its focus on adaptive coping strategies, that were commonly identified by professionals in qualitative data, such as emotional regulation, and a growth mindset. Professionals in this study, demonstrated medium resilient coping as per the BRCS cut-off ranges (Sinclair and Wallston, 2004). While this indicates that most participants possessed a reasonable capacity for adaptive coping, this was not strongly associated with professional well-being outcomes in this sample.

These findings align with existing research suggesting that, although resilience may help buffer the effects of stress, it appears insufficient on its own to mitigate or

reduce the impact of exposure patient suffering, ethical dissonance, and the cumulative impact of work related stress (Sharma and Nicholas, 2025). While resilience may offer some individual benefits, interventions that focus solely on enhancing resilience are unlikely to meaningfully improve professional well-being outcomes in this context.

### Personal Resources

Across all phases of this research, participants described both the costs and benefits of working with plwMND on their personal lives. The intensity of clinical situations often spilled over into personal life, described as feelings of emotional and physical exhaustion after work and, at times persistent thoughts about patients and families. Yet participants also reported a powerful positive impact, including an enhanced sense of gratitude for their own health (and often that of their families), renewed motivation to live life fully, and greater appreciation for small everyday moments.

Participants in the focus group study highlighted personal resources that helped them balance the demands of this work, including hobbies, self-care routines, exercise, and supportive social networks, the open-text survey responses echoed and built on these findings, emphasising the value of maintaining interests outside work and self-care practices. The survey also identified spirituality as a source of support for some respondents, a factor not raised in the focus groups. Another finding from the online survey, was the impact of personal life events, on respondents' well-being at work e.g. parenthood and personal bereavement. Together, these findings underscore the bidirectional relationship between personal wellness and professional well-being and align with wider evidence suggesting that lifestyle practices such as yoga, prayer, meditation, balanced nutrition, and adequate sleep are all associated with reduced stress, compassion fatigue, and burnout (Rocha *et al.*, 2025). Therefore, while responsibility for professional well-being should not rest solely with individual clinicians, and there is a clear need for strong organisational and team-based support structures, strategies that promote personal well-being and a healthy work–life balance should also be encouraged and prioritised among those working in this field.

Table 6.10 summarises recommendations developed from the integrated findings related to the personal resources, skills, and attributes that professionals bring to this work, which were identified as supporting their well-being and capacity to continue providing compassionate care for people living with MND and their families.

**Table 6.10**: Recommendations to Develop Individual Professional Resources, Skills and Attributes to Reduce the Impact of MND Care on Personal and Professional Well-being

**Recommendations:** Develop and strengthen individual professional resources, skills, and attributes to support resilience, adaptive coping, and sustained well-being among healthcare professionals delivering MND care

- **Integrate soft skill development into education and training programmes** alongside clinical knowledge, by incorporating structured opportunities to develop skills such as communication, emotional regulation, teamwork, adaptive problem-solving and flexibility skills
- **Evaluate the impact of interventions such as mindfulness-based approaches that aim to strengthen clinicians' cognitive flexibility, adaptability, creative problem-solving, and tolerance of uncertainty,** and assess their effectiveness in enhancing professional confidence and reducing stress when navigating the dynamic and evolving demands of person-centred care for people living with MND and their families
- **Assess the value of interventions that build emotional intelligence**, **emotional regulation and psychological flexibility**, including approaches such as Acceptance and Commitment Therapy (ACT), in supporting clinicians to manage emotional labour and engage confidently in challenging interactions with plwMND and their families, and recognise, tolerate, and effectively manage their own experiences of discomfort and distress in these encounters
- **Foster workplace cultures that actively support transcendental meaning-making,** by embedding formal reflective practices in which positive feedback, examples of impact, and expressions of gratitude are regularly shared within teams supporting plwMND, helping transform emotionally demanding experiences into sources of purpose, fulfilment, and moral meaning
- **Clinicians working with plwMND should develop and be encouraged to maintain personal well-being plans,** that support them to engage in meaningful activities and interests beyond work that promote balance and help mitigate the emotional demands of challenging clinical roles

**Table 6.11:** Overview of the Meta-Themes and Pillars Developed from the Extended Pillar Integration Process

| Meta-themes | Pillars/Themes | Scoping Review | Focus Group Study | Survey |
|---|---|---|---|---|
| **System** | 1. Service Integration and Care Coordination: Professionals' Experiences Within Fragmented Care Systems | 1. Identified | 1. Identified | 1. Identified |
| | 2. Human and Physical Resources: To Provide the Level of Care Required by People Living with MND | 2. Identified | 2. Identified | 2. Identified |
| **Organisation** | 1. The Role of Workload Flexibility and Autonomy in Supporting Professional Well-Being | 1. Not Identified | 1. Identified | 1. Identified |
| | 2. Recognising Professional Grief and the Emotional Burden of MND Care in the Workplace | 2. Not Identified | 2. Identified | 2. Identified |
| **Interpersonal** | 1. Informal Caregivers: Meeting the Unique Needs of Informal Caregivers of People Living with MND | 1. Identified | 1. Identified | 1. Identified |
| | 2. Multidisciplinary Team Communication and Collegial Relationships: | 2. Identified | 2. Identified | 2. Identified |

| | | | | |
|---|---|---|---|---|
| | Sources of Strain and Support | | | |
| **Individual** | 1. Clinician Risk and Protective Factors Shaping Professional Well-being in MND Care<br><br>2. Clinical Knowledge, Skills and Professional Development: Enhancing Professional Confidence and Competence in MND Care Delivery<br><br>3. Individual Professional Skills, Resources, And Attributes: Supporting Sustained Engagement and Well-Being in MND Care | 1. Not Identified<br><br>2. Identified<br><br>3. Not Identified | 1. Identified<br><br>2. Identified<br><br>3. Identified | 1. Identified<br><br>2. Identified<br><br>3. Identified |

## 6.4 Strengths and Limitations

A key strength of the findings presented in this chapter is the use of a structured and transparent approach to integrating data across the previous three phases of this research, using the Extended Pillar Integration Process (ePIP). By applying the ePIP, this PhD research was able to systematically align, compare, and synthesise findings across multiple data sources, enhancing the rigour, transparency, and trustworthiness of the findings and recommendations drawn. The multilevel framework of professional well-being also provided a robust and empirically grounded lens through which to interpret and present the experiences of HCPs and the influences on their well-being and quality of life identified throughout this research (Penwell-Waines *et al.*, 2018). This framework enabled a nuanced understanding of the interrelated individual, interpersonal, organisational, and

system-level influences shaping care delivery and professional well-being, as described by the research participants. Importantly, this framework also offered a clear and accessible structure for translating findings into practical, multilevel recommendations, supporting the development of targeted strategies that may enhance the experiences of those providing care to plwMND and their families.

While the ePIP provides a structured and transparent method for integrating multiple qualitative and quantitative data sources, it is important to acknowledge that this approach is still in the early stages of development. The seminal paper introducing the ePIP was only published in 2024 (Gauly, Ulahannan and Grove, 2024) and to date, its use has been limited, primarily appearing in a small number of thesis publications with considerable variation in application across studies (Mwape, 2024; Fisher, 2024). In this PhD thesis, the ePIP was applied to systematically integrate findings across three interlinked studies and to situate these integrated results within the broader literature. This approach enhanced contextualisation, provided greater interpretive depth, and strengthened the overall contribution of the study, while also recognising the methodological novelty and evolving nature of this method.

A notable challenge in integrating data across the different phases of this research relates to variation in the samples used. In Phase One (scoping review), HCPs from a wide range of services and disciplines were included in the analysis. In Phase Two (focus group study), the sample comprised Irish HCPs working in both MND-specific and non-specific services, while Phase Three (online survey) focused on professionals working specifically in MND services across Europe. This introduced variation in both geographical context and care setting across the datasets. Although each phase generated valuable and complementary insights, synthesising findings from these differing samples presents interpretive challenges, as highlighted by other authors (Uprichard and Dawney, 2019; Simard *et al.*, 2025). Findings related to non-MND specific services should therefore be interpreted with some caution, given the relatively small number of Irish participants who contributed to this component of the data. While the qualitative study indicated that many of the rewards and challenges of working with this population are shared across disciplines, roles, and service contexts, important differences in levels of exposure, experience, and preparedness

for MND care must be carefully considered when interpreting and generalising the results.

The recommendations presented in this chapter are not intended to be exhaustive and are grounded in the findings of this research. They would benefit from further refinement through consultation with professionals working in the field and from formal consensus-building processes, such as the Nominal Group Technique or the Delphi method (Cary *et al.*, 2023), before being widely adopted within the MND professional community.

## 6.5 Conclusion

This chapter provides a comprehensive, integrated and synthesised outline of the key experiences described by HCPs working with patients and families affected by the devastation caused by MND. It also presents strategies to support professionals in overcoming and managing many of the challenges identified, learning from their experiences and fostering personal and professional development, growth and fulfilment. HCPs typically enter the profession with an innate desire to help those in their care and to alleviate illness and the associated suffering and pain. The perceived inability to effectively help plwMND or their families, was identified as a key driver of professional distress in this research amplified by the consequent exposure to their suffering, pain and multitude of losses.

The findings presented in this chapter align with existing literature on HCP well-being, underscoring that the factors contributing to moral distress, burnout, and diminished professional well-being are diverse, complex, and context dependent. As such, effective interventions must be multilevel and multifaceted, addressing physical, psychological, moral, and social health while cultivating safe, supportive, and ethically grounded work environments (Wakefield *et al.*, 2021; Ooms *et al.*, 2022). This research further demonstrated how professional well-being in this context is shaped by external factors, including organisational support, workplace structure, everyday clinical demands, and team and collegial dynamics, while also being mediated by individual characteristics such as experience, professional role,

knowledge and confidence, psychological disposition, coping resources, and personal wellness. Therefore, both structural and individual factors can either strengthen or diminish professional well-being. Integrated approaches that a combine multiple levels are likely to be the most effective in mitigating work-related stress, reducing psychological harm, maintaining compassionate and high-quality patient care, and retaining skilled personnel within this highly knowledgeable and essential workforce. Future research is now needed to examine the feasibility and acceptability of multilevel interventions and to undertake robust evaluation studies to identify the most effective approaches for reducing the impact of MND care on professional well-being, while also strengthening the personal and professional benefits of this deeply rewarding and meaningful work identified throughout this research.

The final chapter of this thesis, Chapter 7, presents concluding remarks, summarises the key findings and novel contributions of the research, and offers recommendations for practice, policy, and future research, alongside a discussion of the overall strengths and limitations.

# Chapter 7: Conclusion

This research aimed to provide a comprehensive and in-depth understanding of the experiences of HCPs working with MND, explore how these experiences impact their personal and professional well-being, and inform practical recommendations for professional support and workforce sustainability.

This aim was achieved through the application of a multi-phase mixed-methods research design. The unique contributions of each phase, along with the key findings addressing the overall study aim, are outlined in Section 7.1 Novel Contributions of this Research and Key Findings below.

## 7.1 Novel Contributions of this Research and Key Findings

### Phase One: Scoping Review

This is the first systematic synthesis of literature focused exclusively on the experiences of HCPs working with plwMND, and the impact of this work on professional well-being.

#### Key Findings:

- Providing care for plwMND was perceived as distinct from other life-limiting conditions, characterised by high clinical and emotional intensity, rapid and often unpredictable disease progression, and a complex, heterogeneous symptom profile.
- Factors identified as either supporting or restricting professionals from providing desired levels of care for plwMND, included the physical and psychological condition of the patient, the involvement of informal caregivers, multidisciplinary teamwork, communication and collaboration, organisational factors and Covid 19.
- Experiences of emotional exhaustion, burden, frustration, anxiety, stress and burnout, were reported from working with MND patients and families. No studies

measured the impact of this work on professional or occupational well-being outcomes.

- Positive aspects of this work were also identified, including feelings of pride and satisfaction in being able to help, as well as an enhanced appreciation of personal health and life circumstances. Multidisciplinary team support is as an important source of support for professionals, but few other supportive factors were identified.
- The existing literature had not measured potential protective or supportive factors in MND care, nor had it comprehensively explored HCPs' perceived support needs.

## Phase Two: Qualitative Focus Group Study

This PhD research is the first to specifically explore the experiences of Irish HCPs working with people and families affected by MND. This focus group study is also unique in that it captured the perspectives of HCPs across all key services involved in MND care, including those working in both MND specific and non-specific services.

### Key Findings:

- Relational complexity and boundary dilemmas that have not been widely reported in the context of MND patient care were identified.
- There was clear evidence of mortality salience or death anxiety among HCPs, often intensified by interactions with patients and families whose circumstances mirrored their own, confronting them with the realities of human vulnerability and the fragility of life.
- For some professionals, especially those less familiar with working with MND, experiences of stress, anxiety and dread were identified even before engaging or interacting with the plwMND or their family. These responses were often shaped by pre-conceived ideas about the challenges associated with managing the condition or previous challenging experiences.

- This is the first study to address the impact of working with high levels of practical, clinical and ethical uncertainty on professionals providing MND patient care.
- The perceived inability to '*help*' was identified as a key driver of professional distress when working with plwMND, intensified by frequent exposure to situations that reinforced feelings of helplessness, powerlessness and often professional ineffectiveness or futility.
- Many examples of morally challenging situations were identified, when professionals felt restricted from providing what they identified as the appropriate care for a person affected by MND or their family, or when they were unsure about the best course of action. These situations were extracted and further explored in Phase Three of this research.
- This was the first study that directly asked HCPs about their support needs for working with this patient population and identified factors at the system/organisation, team and individual professional level.
- Experiential learning through ongoing work with plwMND and their families supported skill development and confidence in providing MND care, and the professional growth gained from navigating the complexities of this condition was highly valued.
- Vicarious resilience was identified as process through which professionals derived strength, meaning, and personal growth from witnessing MND patients and family's resilience in the face of a very challenging condition and a period of adversity in their lives.
- The emotional impact of this work was identified by HCPs working across all services, and was experienced as sadness, grief, burnout, emotional exhaustion and vicarious trauma. Most identified insufficient support within their organisations and workplaces and relied on external or personal coping mechanisms to manage the emotional and psychological impact.

## Phase Three: Cross-Sectional Online Survey

This is the first study to address the issue of moral distress among HCPs working with people and families affected by MND, and the first pan-European study to measure aspects of professional well-being and quality of life in this workforce. It is also the first study to consider workforce retention and the factors that contribute to intentions to quit or absenteeism in this professional group.

### Key Findings:

- The aggregated emotional toll experienced from working with loss, grief, suffering and death, psychological strain from barriers to providing perceived adequate levels of care and the demands associated with managing an MND caseload, were the main factors associated with consideration of leaving a position in an MND service.
- Secondary traumatic stress was a significant predictor of work-related absenteeism.
- Moral distress is a prevalent experience in this workforce that can impact on both professional quality of life and intention to leave or change position.
- Organisational and system-level barriers were the most frequently reported and distressing contributors to moral distress among professionals caring for plwMND and their families. Additional factors included challenges in addressing the individual needs of family caregivers and the inherent limitations associated with the progressive, terminal, and incurable nature of the condition. While team and professional level factors were reported less frequently, they were still widely endorsed by survey respondents.
- Fewer medical professionals working in MND care reported experiencing moral distress than nurses or AHP's.
- Nurses were identified at reduced risk of both burnout and secondary traumatic stress.

- Experience working with MND was identified as a helpful factor in open-text responses, however, those with the most years of experience working in this field were at the greater risk of experiencing burnout.
- Respondents under 30 reported reduced resilient coping and lower levels of compassion satisfaction.
- Compassion satisfaction is high in this workforce, with internal motivators, such as job satisfaction, the reward of making a meaningful difference in the lives of others, and the opportunity to develop clinical expertise, identified as key drivers for continuing to work in this field.
- Compassion satisfaction was negatively associated with burnout but was not strongly associated or hence considered protective against secondary traumatic stress or moral distress.
- Resilient coping was overall in the '*medium*' range, but was not strongly associated with negative well-being outcomes, suggesting that individual resilience alone is an insufficient a protective factor.
- Interpersonal supports were identified as the most helpful and supportive factor for professionals working with plwMND and their families, encompassing both formal and informal approaches to communication and emotional support within and between teams.

## Phase Four: Integration of Findings from Multiple Datasets

The Extended Pillar Integration Process is a new and emerging method of data integration, this study adds to the growing body of research, demonstrating its application in practice to produce meaningful, practical and action-oriented results. The synthesis of results and findings from this phase represents the first framework offering a comprehensive overview of the support needs of HCPs involved in MND patient care across all levels of the healthcare ecosystem.

Key Findings:

- There is clear evidence that system-level factors significantly influence professional stress, moral distress, burnout, and compassion fatigue. In particular, challenges related to the organisation of integrated and coordinated care, and to accessing adequate human and physical resources to meet the time-sensitive and intensive needs of plwMND and their families. Addressing these issues represents an important opportunity to reduce the impact of this work on HCP well-being.
- The need for organisational support through supportive leadership, recognition of professional grief and emotional distress in the workplace and flexibility and autonomy with workload management were identified to support professionals in managing the demands of MND patient and family care.
- Formal and informal interpersonal approaches were most commonly identified as supportive factors by professionals working with people and families living with MND across all phases of this research. These include standard and regular opportunities for multidisciplinary team communication, encouragement to engage in informal de-briefing, protected and prioritised time for professional supervision and formal team based reflective and supportive interventions such as Schwarts and ethics rounds.
- By integrating multiple data sources, this study is the first to comprehensively identify a range of education, training, and professional development needs among HCPs working with MND across multiple services. It also provides guidance on the content and modes of delivery of education and development programmes that may enhance professional confidence and competence in delivering MND care and help to reduce feelings of anxiety, uncertainty, and helplessness when working with this population.
- Individual professional traits and attributes, including cognitive and psychological flexibility, emotional intelligence, emotional regulation, and tolerance of uncertainty, appear to function as important protective factors against professional stress and reduced psychological well-being for those working with this patient population.

- Individual mechanisms through which professionals cope with the demands of this work, were identified as a process of transcendental meaning making, vicarious resilience and deliberate strategies to maintaining personal wellness and self-care.
- This phase identified that no single approach to sustaining professional well-being is likely to be sufficient; rather, a combination of system, organisational, interpersonal, and individual level, context specific approaches is most likely to be effective in mitigating the impact of this work on professional well-being.

## 7.2 Recommendations for Practice

Detailed recommendations for practice informed by the findings of this research and situated within the broader literature on HCP well-being are presented in Chapter 6 of this thesis. Some of the key overarching recommendations are summarised below.

- HCP well-being should be explicitly recognised and prioritised across all teams, organisations, and services involved in the care of plwMND and their families
- Organisational leaders and managers should be supported through targeted training to recognise the demands of MND care and to adopt compassionate, supportive leadership practices that promote staff well-being and to identify individual clinicians who might be at increased risk of psychological strain.
- Professionals working in this field should have access to regular, structured clinical supervision to support the management of clinical complexity, facilitate emotional processing, and promote ongoing professional development.
- Teams working with plwMND should have access to multidisciplinary forums for communication, both within and beyond their own service or organisation, to support collaborative care planning, clinical reasoning, and emotional support in managing complex cases.

- Informal peer support should be actively encouraged and formally recognised within services as an essential aspect of working in this field, supporting emotional well-being, reducing professional isolation, and facilitating shared reflection on the complex clinical and ethical challenges.

## 7.3 Recommendations for Policy

In the best practice recommendations and clinical guidelines for the management of MND, the support needs of HCPs are commonly overlooked, with the exception of the MND New Zealand Guideline (MND New Zealand, 2022), that briefly mentions the emotional impact for professionals and requirements for support. This research provides convincing evidence that working with patients and families affected by MND can significantly impact the emotional and psychological well-being of HCPs, and of the requirement for multilevel supports. In the most recent European Clinical management guidelines, support needs for HCPs were not addressed.

In line with contemporary national and international workforce and occupational well-being policies, organisations providing supportive care for plwMND and related conditions should establish strategic objectives focused on optimising the well-being of HCPs. This includes implementing robust support structures and recognising the health and well-being of the workforce as central to the delivery of safe, high-quality, and effective patient care. This can provide clear direction for organisations and ensure allocation of sufficient resources to promoting professional well-being and retention.

Policy frameworks should position informal caregiver support as a core component of MND care, recognising its significant influence on both patient outcomes and HCPs' practice and well-being. Investment in caregiver education, respite services, and psychosocial support should be prioritised, as reducing caregiver burden can mitigate pressures on HCPs and support them in delivering sustainable and high-quality care.

## 7.4 Recommendations for Future Research

The exploratory nature of this research has uncovered numerous avenues for future investigation. While several recommendations highlighted in earlier phases of the research were subsequently addressed in later phases, the primary priorities for future research emerging from this work include:

- Future research should further consider the relational complexities inherent in MND care, including how trust and professional boundaries are developed, negotiated, and maintained over time, and the specific supports professionals require to manage these relational demands effectively (4.4.1 Navigating Therapeutic Relationships - Trust and Boundaries).
- Future research should examine the impact of death anxiety and professional grief on HCPs' capacity to engage with plwMND and their families, including which professionals may be most susceptible to this form of distress and how it accumulates or resolves over time (4.4.1 Navigating Therapeutic Relationships - Trust and Boundaries).
- Future research should evaluate the effectiveness of emotional regulation skills, psychological flexibility and emotional intelligence in supporting HCPs to manage emotionally charged encounters, difficult conversations, and the emotional and existential distress inherent in this work (4.4.3 Moral Distress and Helplessness; 4.5.2 Professional Quality of Life).
- Future research should examine the role of professional characteristics such as cognitive flexibility and tolerance of uncertainty in strengthening professionals' capacity to remain present, engaged, and resilient when navigating complex, uncertain, and rapidly evolving clinical situations, as well as evaluate the effectiveness of interventions and educational approaches designed to develop these skills and attributes. (4.4.2 Working with Uncertainty, 6.3.4 The Individual).
- Future research should identify and evaluate robust approaches for measuring moral distress in this population that are suitable for both research and clinical practice, including methods capable of capturing its development and cumulative effects over time (5.4.1 Moral Distress).

- Future research should refine and expand the framework developed in this study to advance a comprehensive and shared understanding of the clinical situations that contribute to moral distress among professionals working with plwMND and their families (5.4.1 Moral Distress).
- Future research should include measures of personal life circumstances and well-being to examine their influence on professional stress, given the intersection between personal and professional well-being identified in this research (4.5.2 Professional Quality of Life).
- Future research should prioritise the development and evaluation of individual, team, organisational and system-level strategies to support HCPs in MND care. Given that individual-level approaches alone are unlikely to address the multifactorial drivers of moral distress and other determinants of professional well-being, combinations of context-specific interventions should be implemented and assessed for their impact on professional quality of life, moral distress, absenteeism, and workforce retention (5.4.3 Helpful and Supportive Factors Sustaining Professionals in MND care).
- Future research should examine training priorities for professionals working in both MND specific and non-specific services and evaluate the effectiveness of different training interventions and delivery modalities in enhancing HCPs' competence and confidence in caring for plwMND across regional, community, and specialist settings (6.3.4 Clinical Knowledge, Skills and Professional Development).
- Future research should consider optimal approaches to delivering neuropalliative care for plwMND, including the development of consensus-based models of care that integrate specialist neurology and palliative care services, and the development of screening and assessment tools to accurately identify and measure neuropalliative care needs (4.4.4 Neuropalliative Care Approach, 6.3.1 The System).
- This research focused specifically on HCPs who were formally employed to provide care and services for plwMND. However, during both phases of data collection, it became apparent that individuals in indirect or supportive roles,

such as administrative and clerical staff, technology technicians involved in setting up specialist equipment, researchers, and other support personnel, may also be significantly affected by working with this condition or by the loss of plwMND in their working life. Although including these groups was beyond the scope of the present study, they represent an important population for future research and should be considered when designing organisational support structures and forums.

## 7.5 Strengths and Limitations

The individual strengths and limitations of each individual study or phase of this research are presented in the respective chapters, while the overall strengths and limitations of the PhD research are presented below.

### Strengths of this Research

This research demonstrates methodological rigor and coherence throughout. It is firmly grounded in a pragmatic epistemological framework, which guided the selection of methods best suited to address the research aim and objectives. A robust mixed-methods approach was employed, with quality indicators and justification for this clearly outlined in Chapter 2. Each phase was conducted using well-justified, appropriate methodologies, carefully aligned with the overarching epistemological stance, and reported in accordance with relevant methodological guidance. This methodological rigor enhances the overall transparency, trustworthiness, validity and practical relevance of the research results.

The use of mixed methods to explore a sensitive topic was a key strength of this research. Issues such as professional stress, burnout, and the challenges associated with working with people affected by MND have the potential to be perceived as professional or personal weaknesses. The qualitative component enabled the researcher to gather rich, in-depth insights into the challenges and rewards of this work, allowing for probing and follow-up questions that captured nuanced experiences. While the online survey complimented this by providing a confidential

and accessible means for participants to share their experiences without the influence of social desirability bias. Together, these methods allowed the research to balance depth and breadth, enhancing the overall understanding of the professional impact of this work while maintaining sensitivity to participant experiences.

Recruitment strategies were highly effective in this research. In the qualitative phase, all key targeted services participated, and the full range of disciplines involved in MND patient care were represented. Likewise, the online survey captured responses from all major professional groups, ensuring that the findings are broadly representative of the MND workforce.

## Limitations of this Research

Although the study achieved a broadly representative sample, the potential for selection bias must be acknowledged. Participation in all phases was voluntary, which may have resulted in an overrepresentation of individuals with a particular interest in the topic and a potential underrepresentation of those experiencing the greatest work-related stress. Additionally, social desirability may have influenced participation in the focus groups and may have moderated the responses of those who took part, in the presence of colleagues.

A limitation of this research concerns the development of the 24 clinical statements used in the Phase 3 online survey to examine contributors to moral distress. Although these items were widely endorsed by respondents, they were primarily derived from qualitative focus group data collected in Ireland and may therefore reflect context-specific experiences. While the international survey suggests broad relevance, some system or culture specific aspects of moral distress in other healthcare settings may not have been fully captured.

The recommendations generated in Phase Four, particularly those relating to non-MND specific services, would benefit further validation using larger, more representative samples of professionals across diverse care settings, as well as more formal, consensus-based research methods. While some services, most notably MND-specific services, were well represented, others, such as primary care and residential care, contributed only a small number of participants relative to the size

of their workforce. This imbalance limits the generalisability of certain findings. Furthermore, differences in sample characteristics between the qualitative phase (Phase Two) and the predominantly quantitative phase (Phase Three) created challenges for integrating findings in Phase Four, potentially influencing the coherence and comparability of the final recommendations.

## 7.6 Conclusion

This PhD research has identified that working with people and families affected by MND can both positively and negatively affect the personal and professional well-being of HCPs involved in providing their care. The practical, emotional and ethical complexities of these roles can place professionals at risk of moral distress, compassion fatigue, burnout and intentions to leave their role or position. We identified a number of antecedents that can contribute to experiences of moral distress in this population, with higher intensities of distress from these situations associated with reduced professional quality of life and intention to leave their role or profession. Moral distress, however, was not the sole contributing factor to emotional distress or other aspects of professional well-being. Additional factors, including the depth of relationships formed with patients and families, the inevitability of patient loss and death, the continuous changes in patients' condition, and exposure to high levels of patient and family distress, were factors also identified as contributing to emotional and psychological strain from this work. It is also important to highlight the significant personal and professional benefits that were associated with working with plwMND, reflected in the high levels of compassion satisfaction, strong intentions to remain working in this area of practice in the future and the significant levels of meaning and purpose many professionals attributed to their roles. Professionals described benefits such as opportunities to work closely with supportive MDTs and colleagues, valuable learning and professional development opportunities, and a renewed sense of gratitude and appreciation for what is important in life. The benefits of this work, however, cannot be fully realised without the provision of adequate supports to counterbalance and help to offset the

undeniable challenges faced by those supporting these patients and families in their daily work.

Supporting the well-being of HCPs requires multifaceted approaches, as was clear from the issues identified and responses provided by participants throughout all stages of this research. Importantly, although certain sources of professional distress and emotional strain varied across disciplines and care settings, the emotional impact was largely universally experienced and hence should be recognised at policy, system, organisational, team, and individual clinician levels. To reduce the moral and emotional strain associated with working within complex, often unsuitable and unjust systems of care, systemic changes should be considered to reduce primary sources of distress. Organisational cultures and leadership practices should acknowledge the ethical, emotional and practical demands of this work, with support structures in place for all staff and additional services available for those identified as most at risk. Interpersonal and team-based approaches are vital for reducing clinical and ethical uncertainty and for providing essential emotional support and de-briefing opportunities. Education, training and professional development opportunities should be consistently available to address learning needs and enhance perceived competence in managing the complexities of MND patient care. Finally personal skills and resources such as individual clinician resilience, emotional intelligence and regulation skills, adaptability and cognitive flexibility and personal coping resources appear to offer some protection but are unlikely to be sufficient in isolation without concurrent system, organisational and team-based support. Future research is needed to develop and evaluate interventions aimed at reducing the impact of MND care on professional quality of life, while also strengthening retention, engagement, and the capacity to deliver consistent, person-centred, and compassionate care across the MND trajectory.

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## Appendices:

### **Appendix A**: Example Search Strategy (EMBASE)

| | |
|---|---|
| 1. | 'motor neuron disease'/exp |
| 2. | ((motoneuron  OR 'motor neuron' OR 'motor neurone') NEAR/2 disease*):ti,ab,kw |
| 3. | 'acute motor axonal neuropath*':ti,ab,kw |
| 4. | ('amyotrophic lateral sclerosis' OR 'als (amyotrophic lateral sclerosis)' OR 'lou Gehrig* disease' OR 'als dementia'):ti,ab,kw |
| 5. | 'primary lateral sclerosis':ti,ab,kw |
| 6. | ('progressive muscular atroph*' OR 'progressive spinal muscle atrophy*' OR 'progressive spinal muscular atrophy*' OR 'progressive bulbar palsy'):ti,ab,kw |
| 7. | #1 OR #2 OR #3 OR #4 OR #5 OR #6 |
| 8. | ((‘health system*’ OR ‘healthcare system*’ OR ‘healthcaresystem*’ OR ‘health service*’ OR ‘healthcare service*’ OR ‘healthcareservice*’ OR ‘healthcare organi?ation*’ OR ‘healthcareorgani?ation*’) NEAR/4 (experience OR experiences OR impact* OR challenge* OR perspective* OR perception*)):ti,ab,kw |
| 9. | ((‘Health care’ OR healthcare OR health OR rehabilitation OR therapy OR clinical OR professional) NEAR/3 (experience OR experiences OR impact* OR challenge* OR perspective* OR perception* OR view*)):ti,ab,kw |
| 10. | ((Neurologist* OR nurs* OR dietitian* OR 'occupational therapist*' OR physiotherapist* OR physician* OR clinician* OR doctor* OR 'speech and language therapist*' OR 'speech & language therapist*' OR 'speech pathologist*' OR therapist* OR clinician* OR 'social worker*' OR psychologist* OR neuropsychologist* OR neuro-psychologist*) NEAR/3 (experience OR experiences OR impact* OR challenge* OR perspective* OR perception* OR attitude* OR affect* OR view* OR concern*)):ti,ab,kw |
| 11. | #8 OR #9 OR #10 |
| 12. | 'healthcarepersonnel'/exp OR 'health personnel attitude'/exp OR 'professional-patient relationship'/exp OR 'professional-patient relationship'/exp |
| 13. | ((‘Health care’ OR healthcare OR health OR rehabilitation OR therapy OR clinical) NEAR/3 (professional* OR personnel OR staff)):ti,ab,kw |
| 14. | 'multidisciplinary team'/exp |
| 15. | ('multidisciplinary team*' OR 'multidisciplinary care'):ti,ab,kw |
| 16. | (Neurologist* OR nurs* OR dietitian* OR 'occupational therapist*' OR physiotherapist* OR physician* OR clinician* OR doctor* OR 'speech and language therapist*' OR 'speech & language therapist*' OR 'speech pathologist*' OR 'social worker*' OR psychologist* OR neuropsychologist* OR neuro-psychologist*):ti,ab,kw |

**Appendix B:** Data Collection Tool Developed and Used in the Scoping Review

| Study Title | Author & Year | Country | Study design | Participants/ Profession(s) | Healthcare Setting | Experience as described by the HCP | Impact on the HCP |
|---|---|---|---|---|---|---|---|
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## ***Appendix C:*** PRISMA-ScR Reporting Guideline

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a scoping review. | 35 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives. | 36 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach. | 37-39 |
| Objectives | 4 | Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives. | 38 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number. | 39<br>Protocol Registered on OSF. Link included in report. |
| Eligibility criteria | 6 | Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale. | 40 |
| Information sources* | 7 | Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed. | 40-41 |
| Search | 8 | Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated. | Appendix A p.337 |
| Selection of sources of evidence† | 9 | State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review. | 41 |
| Data charting process‡ | 10 | Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done | 41<br>Data extraction tool provided in Appendix B. p.338 |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| | | independently or in duplicate) and any processes for obtaining and confirming data from investigators. | |
| Data items | 11 | List and define all variables for which data were sought and any assumptions and simplifications made. | 41 |
| Critical appraisal of individual sources of evidence§ | 12 | If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate). | N/A critical appraisal of included sources was not completed as not relevant for aim of the review. |
| Synthesis of results | 13 | Describe the methods of handling and summarizing the data that were charted. | 42 |
| **RESULTS** | | | |
| Selection of sources of evidence | 14 | Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram. | 42<br>PRISMA flow diagram Figure 3.1 included in the report. |
| Characteristics of sources of evidence | 15 | For each source of evidence, present characteristics for which data were charted and provide the citations. | 44-46 |
| Critical appraisal within sources of evidence | 16 | If done, present data on critical appraisal of included sources of evidence (see item 12). | N/A not completed. |
| Results of individual sources of evidence | 17 | For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives. | Appendix D. p341-367 |
| Synthesis of results | 18 | Summarize and/or present the charting results as they relate to the review questions and objectives. | 47-64 |
| **DISCUSSION** | | | |
| Summary of evidence | 19 | Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups. | 65 |
| Limitations | 20 | Discuss the limitations of the scoping review process. | 68 |
| Conclusions | 21 | Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps. | 70 |
| **FUNDING** | | | |
| Funding | 22 | Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review. | This research is funded by the HRB – acknowledged in publication. |

**Appendix D**: Table of Studies Included in the Scoping Review and Key Study Characteristics

| Author | Year | Title | Country | Study design & methods. | Number of health care professional participants | Healthcare settings | Data extracted as relevant to scoping review |
|---|---|---|---|---|---|---|---|
| **Chapman et al.** | 2021 | Communication Surrounding Initiation and Withdrawal of Non-Invasive Ventilation in Adults with Motor Neuron(e) Disease: Clinicians and family members perspectives | Australia | Interpretative descriptive qualitative design. Semi-structured interviews. Thematic analysis. | Healthcare professionals (*n*=19) Nurse (*n*=8) Medical (*n*=9) Physiotherapist (*n*=1) Social Worker (*n*=1) | Specialist palliative care services, Hospital, Support (voluntary) organisation | - Engaging in difficult conversations/ timing of communication<br>- Time to deliver adequate care<br>- Managing patient and family emotion<br>- Patient and family psychological adjustment<br>- Managing cognitive and behavioral changes<br>- Multidisciplinary team communication and collaboration<br>- Emotional impact of involvement with withdrawal of non-invasive ventilation |
| **Aoun et al.** | 2016 | Breaking the News of a Diagnosis of Motor Neurone Disease: A National Survey of Neurologists Perspectives | Australia | Anonymous online survey. | Healthcare professionals (*n*=69) Medical (*n*=69) | Multidisciplinary Clinic Hospital | - Engaging in difficult conversations<br>- Managing patient and family emotion<br>- Time to deliver adequate care<br>- Being honest without taking away hope<br>- Clinician experience<br>- Emotional impact of communicating a terminal diagnosis |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Brown.** | 2003 | User, Carer and Professional Experiences of Care in Motor Neurone Disease | United Kingdom | Hermeneutic phenomenological qualitative design. | Healthcare professionals (n=9) Speech and Language Therapist (*n*=1) Nurse (*n*= 2) Dietitian (*n*=1) Social Worker (*n*=1) Medical (*n*=2) Physiotherapist (*n*=1) Occupational Therapist (*n*=1) | Community Others not specified | - Intensity of care required<br>- Individual approach<br>- Support required by informal caregivers<br>- Clinician experience<br>- Clinician knowledge/ confidence<br>- Ability to make a difference<br>- Resource limitations – personnel, time, equipment, external economics<br>- Multidisciplinary team communication and collaboration<br>- Frustration – inability to achieve ideals of care<br>- Emotional involvement<br>- Taking on the '*burden of grief*' |
| **Faull et al.** | 2016 | The Emotional Issues for Health Professionals Involved in the Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease | United Kingdom | *Conference Abstract Qualitative interviews. Thematic Analysis | Healthcare professionals (*n*=50) *Breakdown of participants professional background is not provided. | Not specified | - Above standard role<br>- Legal, moral, ethical concerns<br>- Emotional impact of involvement with withdrawal of non-invasive ventilation '*personal sadness*'<br>- Long term emotional impact<br>- Positive experience of fulfilling patient's wishes and ensuring a '*good death*' |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **McConigley et al.** | 2014 | Staying Just One Step Ahead: Providing Care for Patients with Motor Neurone Disease. | Australia | Descriptive, exploratory qualitative design. Interviews and focus groups. Thematic content analysis. | Healthcare professionals (*n*=31)<br>Nurse (*n*=8)<br>Occupational Therapist (*n*=6)<br>Case coordinator (*n*=5)<br>Medical (*n*=3)<br>Physiotherapist (*n*=3) Speech Pathologist (*n*=1)<br>Complementary Therapist (*n*=1)<br>Counsellor (*n*=1)<br>Dietitian (*n*=1)<br>Prosthesis (*n*=1)<br>Chaplain(*n*=1)<br>*some professionals listed more than one professional role. | Not specified | - Distinct from patients with other life limiting conditions – unique care needs<br>- Individualised care<br>- Importance of anticipatory care<br>- Challenges responding to rapid disease progression<br>- Patient and family psychological adjustment<br>- Clinician experience<br>- Clinician knowledge/confidence<br>- Time to provide adequate care<br>- Challenges with motor neurone disease associated communication impairment<br>- Developing relationships with informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Engaging in difficult conversations |
| **Bromberg et al.** | 2011 | A Survey of Stress Among Amyotrophic Lateral Sclerosis Care Providers | USA | Quantitative online survey | Healthcare professionals (*n*=63)<br>Medical (*n*=32)<br>Clinic managers (*n*=31) (23 clinic managers were nurses)<br>8 others (professional | Multidisciplinary clinics | - Job satisfaction<br>- Staff turnover/ intention to quit<br>- Clinician experience<br>- Organisational barriers – lack of personnel, time, finances<br>- Emotional involvement<br>- Clinician stress at each critical stage (diagnosis, managing care and death) influenced by patient characteristics, global circumstances, patient disease |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | background not specified) | | factors and acceptance of disease<br>- Emotional impact of communicating a terminal diagnosis<br>- Stress of working with amyotrophic lateral sclerosis not formally addressed |
| **Gamskjaer et al.** | 2021 | Investigating Job Satisfaction in Palliative Rehabilitation: Reflections and Perspectives of Health Professionals Working with Amyotrophic Lateral Sclerosis | Denmark | Hermeneutic phenomenological qualitative design based on Paul Ricoeur's interpretation theory. | Healthcare professionals (*n*=12)<br>Nurse (*n*=4)<br>Psychologist (*n*=2)<br>Occupational Therapist(*n*=1)<br>Physiotherapist (*n*=2)<br>Social Worker (*n*=2)<br>Medical (*n*=1) | Multidisciplinary Palliative Rehabilitation Team | - Job satisfaction<br>- Ability to make a difference in the lives of others<br>- Receiving gratitude<br>- Clinician knowledge<br>- Multidisciplinary team communication and collaboration<br>- Gratitude for own health and personal life<br>- Emotional involvement<br>- Emotional exhaustion |
| **Mitsumoto et al.** | 2007 | Palliative Care for Patients with Amyotrophic Lateral Sclerosis | USA | Case study with clinical reflection | Healthcare professionals (*n*=1)<br>Medical (*n*=1) | Palliative care | - Multidisciplinary team communication and collaboration<br>- Emotional involvement – vulnerability to stress and burnout<br>- Experiencing '*extraordinary burdens and extraordinary opportunities providing expert* |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | *care throughout this tragic illness'* |
| **Lerum et al.** | 2017 | Healthcare Professionals Accounts of Challenges in Managing Motor Neurone Disease in Primary Healthcare: A Qualitative Study. | Norway | Qualitative Semi-structured interviews | Healthcare professionals (*n*=18) Occupational Therapist (*n*=3) Nurse (*n*=11) Hospice Worker (*n*=4) (professional background not specified) | Community/ primary care Hospice | - Intensity of care required, prioritised over patients with other conditions<br>- Importance of developing relationships with patients and families<br>- Patient and family psychological adjustment<br>- Support required by informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Clinician knowledge/skill |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | - Clinician experience<br>- Staff turnover and retention challenges |
| **Carter et al.** | 1998 | Health Professionals Responses to Multiple Sclerosis and Motor Neurone Disease | New Zealand | Quantitative Questionnaire with open and closed questions | Healthcare professionals (*n*=317)<br>Nurse (*n*=138)<br>Physiotherapist (*n*=59)<br>General practitioners (*n*=43)<br>Occupational Therapists, Speech and Language Therapists, Social Workers and Dietitians (*n*=77) breakdown not provided. | Hospital<br>General practices<br>Hospice | - Professionals felt less confident in their ability to manage the care of people with motor neurone disease than those with multiple sclerosis<br>- Clinician knowledge and experience<br>- Patient and family psychological adjustment<br>- Managing the rate of disease progression<br>- Ability to convey hope<br>- Resource and service-related issues – difficulty accessing services, finances and medical devices<br>- Multidisciplinary team communication and collaboration |
| **Erlen et al.** | 1990 | Making an Ethical Decision in the Home Setting: The Case of Stan | USA | Case study | Healthcare professionals (*n*=1)<br>Nurse (*n*=1) | Community | - Intensity of care required<br>- Impacting ability to provide care for other patients<br>- Overwhelmed by the multitude of clinical problems and when faced with making complex decisions about appropriate |

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|---|---|---|---|---|---|---|---|
| | | | | | | | clinical care alone in the patients home<br>- Moral and ethical concerns – autonomy vs beneficence<br>- Support required by informal caregivers<br>- Staff turnover and retention |
| **Carroll-Thomas** | 1993 | Ethics and the Clinician: The Daily Experience with Motor Neurone Disease | USA | Clinical reflection | Healthcare professionals (*n*=1) Speech and Language Therapist (*n*=1) | Not specified | - Importance of anticipatory care<br>- Ethical concerns – patient choice vs beneficence<br>- Balancing the needs of patients and informal caregivers<br>- Managing expectations<br>- Funding for assistive devices<br>- Resource allocation |
| **De Carvalho Costa et al.** | 2020 | Palliative Care to Patients with Amyotrophic Lateral Sclerosis: Experiences of Physiotherapists in a Hospital Setting | Brazil | Descriptive exploratory qualitative design. Semi-structured interviews. Content analysis. | Healthcare professionals (*n*=8) Physiotherapist(*n*=8) | Hospital | - Multidisciplinary team communication and collaboration<br>- Clinician knowledge<br>- Ability to make a difference<br>- Emotional involvement<br>- Lack of education about how to manage the emotional and moral suffering from this work |
| **Hetzler.** | 2021 | Empowering People with ALS | USA | Clinical reflection | Healthcare professionals (*n*=1) Physiotherapist (*n*=1) | ALS and Huntington's Disease Multidisciplinary Team Clinic | - Patient and family psychological adjustment<br>- Access to resources<br>- Job satisfaction<br>- Emotional involvement |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | - Ability to make a difference and help people when they need it most<br>- Receiving gratitude | |
| **Cornwell.** | 2016 | Clinical Issues for Working with Patients and Family Members Dealing with Amyotrophic Lateral Sclerosis | USA | Clinical Reflection | Healthcare professionals (*n*=1)<br>Psychotherapist (*n*=1) | ALS clinic | - Managing patient and family emotion<br>- Emotional involvement<br>- Ability to make a difference<br>- Perspective | |
| **Ruffell el al.** | | 2013 | Healthcare Professionals Views on the Provision of Gastrostomy and Non-invasive Ventilation to Amyotrophic Lateral Sclerosis Patients in England, Wales and Northern Ireland. | United Kingdom | Online survey | Healthcare professionals (*n*=177)<br>Medical (*n*=99)<br>Nurse (n=25)<br>Physiotherapist (n=9)<br>Occupational Therapist (n=3)<br>Speech and Language Therapist (n=11)<br>Dietitian (n=18)<br>Care-coordinator (n=7) | Multidisciplinary clinics<br>Hospital<br>Palliative Care | - Individualised care<br>- Timing of conversations<br>- Clinician knowledge<br>- Multidisciplinary team communication and collaboration | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | Not Specified (n=5) | | |
| **Martin et al.** | 2016 | Decision Making about Gastrostomy and Non-invasive Ventilation in Amyotrophic Lateral Sclerosis | United Kingdom | Qualitative Interviews Thematic analysis | Healthcare professionals (*n*=19)<br>Medical (*n*=9)<br>Nurse (*n*=7)<br>Dietitian (*n*=1)<br>Speech and Language Therapist (*n*=1)<br>Care Coordinator (*n*=1) | Hospital<br>Community<br>Specialist MND clinics<br>Hospice | - Individualised approach<br>- Importance of anticipatory care<br>- Engaging in difficult conversations/ timing of communication<br>- Patient and family psychological adjustment<br>- Influence of informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Clinician experience |
| **Gale.** | 2015 | Assisting Patients with Motor Neurone Disease to Make Decisions About Their Care | United Kingdom | Case study | Healthcare professionals (*n*=1)<br>Nurse (*n*=1) | Hospice | - Patient and family psychological adjustment<br>- Individualised approach<br>- Ethical issues – patient choice vs beneficence<br>- Engaging in difficult conversations about advanced care planning |
| **Hogden et al.** | 2012 | Engaging in Patient Decision Making in Multidisciplinary Care for Amyotrophic Lateral | Australia | Qualitative interviews Thematic analysis | Healthcare professionals (*n*=32)<br>Medical (*n*=9)<br>Nurse (*n*=5)<br>Physiotherapist (*n*=4)<br>Social Worker (*n*=2) | Acute hospital<br>Community rehabilitation<br>Palliative care<br>ALS clinics | - Individualised approach<br>- Importance of anticipatory care<br>- Managing family dynamics<br>- Balancing the needs of patients and their families<br>- Patient and family psychological adjustment |

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| | | Sclerosis: The Views of Health Professionals | | | Occupational Therapist (*n*=3)<br>Speech and Language Therapist (*n*=2)<br>Dietitian (*n*=2)<br>Care Coordinator (*n*=3)<br>Research Staff (*n*=1)<br>Volunteer (*n*=1) | Motor Neurone Disease Association | - Managing cognitive and behavioural changes<br>- Responding to rapid disease profession '*crisis situations'*<br>- Clinician knowledge<br>- Managing expectations<br>- Time sensitive care<br>- Timing of communication<br>- Resources – funding, access to services<br>- Multidisciplinary team communication and collaboration<br>- Stress and frustration in relation to delays with decision making and acquiring resources to deliver care required by the patient at that time<br>- Frustration with constraints imposed by factors outside of professionals control |
| **Oliver et al.** | 2010 | Some Difficult Decisions in ALS/MND | United Kingdom | Clinical reflection with expert opinion | Healthcare professionals (*n*=2)<br>Medical (*n*=2). | Hospice/ palliative care<br>MND care centre | - Challenges with motor neurone disease associated communication impairments<br>- Patient and family psychological adjustment<br>- Balancing the needs of patients and informal caregivers<br>- Multidisciplinary team communication and collaboration |

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| **Dengler et al.** | 1997 | Impact of Riluzole on the Relationship Between Patient and Physician | Germany | Clinical reflection with expert opinion | Healthcare professionals (*n* =2)<br>Medical (*n* =2) | Not specified | - Difficulty communicating a terminal diagnosis<br>- Managing patient and family emotion<br>- Ability to convey hope and optimism<br>- Individualised approach<br>- Patients strong interest in ongoing research<br>- Influence of informal caregivers on the patient-clinician relationship<br>- Resources – delays with administration, finances and obtaining resources more problematic for this population<br>- Difficulty coping with the inability to effectively intervene |
| **Siewers et al.** | 2013 | Experiences with Using Mechanical In-exsufflation in Amyotrophic Lateral Sclerosis | Norway | Qualitative semi-structured interviews<br>Thematic content analysis | Healthcare professionals (*n*=3)<br>Nurse (*n*=3) | Community | - Clinician knowledge and skill<br>- Intensity of care required - patients' dependence on professional caregivers<br>- Clinician confidence with the use of aids and devices<br>- Multidisciplinary team communication and collaboration<br>- Time to provide appropriate care |
| **Phelps et al.** | 2017 | Withdrawal of Ventilation at the Patients | United Kingdom | Retrospective thematic analysis of qualitative interviews | Healthcare professionals (n=24)<br>Medical (n=24) | Hospital<br>Community<br>Residential Care | - Legal, moral and ethical dilemmas – withdrawing non-invasive ventilation at the end-of-life |

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| | | Request in MND: A Retrospectiv e Exploration of the Ethical and Legal Issues that Have Arisen for Doctors in the UK. | | | | Palliative Care | - Challenges of motor neurone disease associated communication impairments<br>- Support required by informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Emotional involvement<br>- Stress and fear about legality of the withdrawing ventilationAnxiety about perception of hastening death |
| **Faull et al.** | 2014 | Issues for Palliative Medicine Doctors Surrounding the Withdrawal of Non-invasive Ventilation at the Request of a Patient with Motor Neurone Disease: A Scoping Study. | United Kingdom Ireland | Mixed categorical and free text online questionnaire. Descriptive statistics and thematic analysis using constant comparison based on grounded theory | Healthcare professionals (*n*=130) Medical (*n*=130) | Not specified | - Moral and ethical uncertainty – withdrawing non-invasive ventiliation<br>- Identified as more stressful than most other areas of practice<br>- Intensity of care<br>- Patient and family psychological adjustment<br>- Managing the emotion of others<br>- Support required by informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Difficulty ensuring autonomy with motor neurone disease associated communication impairments and/or cognitive and behavioural changes |

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| | | | | | | | - Emotional involvement – stress, anxiety, emotional drain |
| **Phelps et al.** | 2022 | Withdrawal of Assisted Ventilation at the Patients Request in MND/ALS: A Retrospectiv e Exploration of the Ethical and Legal Issues Concerning Relatives, Nurses and Allied Health Care Professional s. | United Kingdom | Retrospective analysis of qualitative interviews<br>Constant comparison analysis based on grounded theory | Healthcare professionals (*n*=25)<br>Nurse (*n*=19)<br>Physiologist (*n*=2)<br>Physiotherapist (*n*=2)<br>Social Worker (*n*=1)<br>MND care coordinator (n=1) | Community Palliative Care Motor Neurone Disease Association | - Legal, moral and ethical uncertainty – withdrawal of non-invasive ventilation<br>- '*Ethical burden and emotional stress'*<br>- Intensity of care – time burden<br>- Above '*usual practice'*<br>- Clinician knowledge and experience<br>- Multidisciplinary team communication and collaboration<br>- Support required by informal caregivers<br>- Fear of ethical and legal repercussions<br>- Rewarding experience – helping patients and families through difficult decisions and processes<br>- Emotional involvement – profound lasting effects due to emotional intensity of events surrounding the withdrawal<br>- Fear and anxiety about perception of hastening death |

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| **Baxter et al.** | 2013 | The Use of Non-invasive Ventilation at End of Life in Patients with Motor Neurone Disease: A Qualitative Exploration of Family Carer and Health Professional Experiences | United Kingdom | Longitudinal qualitative study<br>Thematic analysis | Healthcare professionals (*n*=15)<br>Physiotherapist (*n*=2)<br>Occupational Therapist (*n*=3)<br>Nurse (*n*=8)<br>Medical (*n*=2) | Community/ Primary care<br>Palliative care<br>Neurology support team | - Managing rapid disease progression<br>- Timing of communication<br>- Patient and family psychological adjustment<br>- Support required by informal caregivers<br>- Clinician knowledge<br>- Positive experience of providing comfort and reassurance for the patient/ family |
| **LeBon et al.** | 2010 | Case Report: Maintaining and Withdrawing Long-term Invasive Ventilation in a Patient with MND/ALS in a Home Setting | United Kingdom | Case Report | Healthcare professionals (*n*=2)<br>Medical (*n*=2) | Specialist palliative care | - Legal, moral and ethical uncertainty – withdrawing treatment at a patient's request<br>- Intensity of care *'exceptional team effort'*<br>- Engaging in difficult conversations<br>- Patient and family psychological adjustment<br>- Multidisciplinary team communication and collaboration<br>- Emotional involvement – emotional support required by professional care team |

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| **Oliver.** | 2004 | Ventilation in Motor Neurone Disease: Difficult Decisions in Difficult Circumstances | United Kingdom | Case study with clinical reflection | Healthcare professionals (n=1) Medical (n=1) | Hospice/ palliative care | - Engaging in difficult conversations<br>- Ethical dilemmas - balancing the needs of patients and family caregivers Challenges with motor neurone disease associated communication impairments<br>- Patient and family psychological adjustment<br>- Multidisciplinary team communication and collaboration |
| **Olesen et al.** | 2022 | Reflections of Family Caregivers and Health Professionals on the Everyday Challenges of Caring for Persons with Amyotrophic Lateral Sclerosis and Cognitive Impairments a Qualitative Study | Denmark | Qualitative focus group and semi-structured individual interviews. Interpretative description analysis guided by theory of sense of coherence | Healthcare professionals (*n*=8) Nurse (*n*=3), Occupational Therapist (*n*=2), Social care assistants (*n*=3) | Community | - Intensity of care – constant progression<br>- Managing cognitive and behavioural changes<br>- Support required by informal caregivers<br>- Time to provide adequate care<br>- Clinician knowledge<br>- Managing expectations<br>- Clinician experience<br>- Multidisciplinary team communication and collaboration<br>- Emotional involvement – emotional distancing |

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| **Ushikubo et al.** | 2021 | Practical Measures for Dealing with the Struggles of Nurses Caring for People with Amyotrophic Lateral Sclerosis Comorbid with Cognitive Impairment in Japan | Japan | Cross-sectional qualitative descriptive design with a questionnaire survey and focus group interviews | Healthcare professionals (*n*=139)<br>Nurse (*n*=137)<br>Social Worker (*n*=1)<br>Medical (*n*=1) | Community/ public health centres<br>Hospital | - Intensity of care – time burden – nurse exhaustion<br>- Ethical dilemmas - patient autonomy vs beneficence<br>- Patient and family psychological adjustment<br>- Managing cognitive and behavioural changes<br>- Challenges ensuring autonomy with motor neurone disease associated communication impairments<br>- Support required by informal caregivers<br>- Multidisciplinary team communication and collaboration |
| **Crockford et al.** | 2017 | Clinicians Attitudes Towards Cognitive and Behavioural Screening in Motor Neurone Disease | Scotland United Kingdom | Structured qualitative interviews consisting of both open ended and forced choice questions Thematic analysis | Healthcare professionals (*n*=14)<br>Medical (*n*=5)<br>Psychologist (*n*=4)<br>ALS clinical care specialists (n=5)<br>*Profession not specified | NHS health boards | - Managing cognitive and behavioural changes<br>- Multidisciplinary team communication and collaboration<br>- Patient and family psychological adjustment<br>- Clinician knowledge<br>- Lack of resources – time, staffing levels, access to training and appropriate assessment tools<br>- Geographical variation in services available |

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| **Gray et al.** | 2022 | International Evaluation of Current Practices in Cognitive Assessment for Motor Neurone Disease | Africa (South Africa)<br>Asia (China)<br>Australia/New Zealand<br>Europe (Austria, Belgium, Bosnia Herzegovina, Croatia, Denmark, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden).<br>North America (Canada)<br>South America (Peru, Colombia) | Online survey consisting of quantitative closed responses and open-ended text responses<br>Descriptive statistics and framework analysis methods | Healthcare professionals (*n*=80)<br>Medical (*n*=47)<br>Nurse (*n*=4)<br>Psychologist (*n*=7)<br>Clinical care coordinator (*n*=6)<br>Allied health professional (*n*=7)<br>*Breakdown of AHPs not provided<br>Other/not disclosed (*n*=10) | Specialist MND/ ALS clinics | - Managing cognitive and behavioural changes<br>- Time to provide adequate care<br>- Clinician knowledge<br>- Patient and family psychological adjustment<br>- Resources – staffing |

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| **O'Brien et al.** | 2022 | Palliation in a Pandemic: The Human Cost of Achieving the Greater Good | Ireland | Case study | Healthcare professionals (*n*=1)<br>Medical (*n*=1) | Hospice/ Palliative care | - Motor neurone disease patient viewed by palliative care staff as an '*exceptional case'*<br>- Challenges delivering motor neurone disease care during COVID 19<br>- Ethical dilemmas – visiting policies and end-of-life care<br>- Challenges associated with motor neurone disease associated communication impairment<br>- Emotional involvement |
| **Coates et al.** | 2021 | Patient, Carer and Healthcare Professional Perspectives on Increasing Calorie Intake in Amyotrophic Lateral Sclerosis | United Kingdom | Multi-center qualitative design<br>Focus group interviews with template data analysis approach. | Healthcare professionals (*n*=51)<br>Medical (*n*=8)<br>Nurse (*n*=10)<br>Dietitian (*n*=15)<br>Speech and Language Therapist (*n*=6)<br>Occupational Therapist (*n*=3)<br>Physiotherapist (*n*=2)<br>Community Outreach (*n*=1)<br>Psychologist (*n*=1)<br>Care Coordinator (*n*=5) | Multidisciplinary clinics | - Importance of anticipatory care<br>- Managing rapid disease progression<br>- Individualised approach<br>- Time to provide adequate care<br>- Resources – staffing, funding, inconsistent team composition<br>- Geographical variation in services available<br>- Clinician knowledge and experience<br>- Patient and family psychological adjustment<br>- Cognitive and behavioural changes<br>- Support provided by informal caregivers |

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| **Zarotti et al.** | 2019 | Healthcare Professionals Views on Psychological Factors Affecting Nutritional Behaviour in People with Motor Neurone Disease: A Thematic Analysis. | United Kingdom | Qualitative focus group interviews Thematic analysis | Healthcare professionals (*n*=47) Dietitian (*n*=25) Medical (*n*=2) Clinic coordinator (*n*=2) Nurse (*n*=11) Physiotherapist (*n*=1) Speech and Language Therapist (*n*=6) | Community Hospital | - Managing disease progression<br>- Clinician knowledge<br>- Individual approach<br>- Patient and family psychological adjustment | |
| **James et al.** | 2018 | Healthcare Professionals Perspectives of Multidisciplinary Home-based E-health for Amyotrophic Lateral Sclerosis | Australia | *Conference abstract Qualitative focus group interviews Stepwise inductive approach to data analysis | Healthcare professionals (*n*=15) *Professional backgrounds not reported | Specialist ALS clinics | - Individualised approach<br>- Resource limitations<br>- Importance of relationship building | |
| **Andrews et al.** | 2020 | Amyotrophic Lateral Sclerosis Care and Research in the United | USA | Quantitative online survey Descriptive statistics | Healthcare professionals (*n*=61) *Professional backgrounds not reported | ALS clinics | - Challenges delivering care during COVID 19 – inability to deliver optimal care | |

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| | | States During the COVID-19 Pandemic: Challenges and Opportunities | | | Surveys disseminated to members of the Northeast ALS (NEALS) Consortium | | | |
| **Musson et al.** | 2022 | Impact of the COVID-19 Pandemic on Amyotrophic Lateral Sclerosis Care in the UK. | United Kingdom | Cross-sectional online survey<br>Combination of closed ended and open ended questions<br>Descriptive and inferential statistics and thematic analysis | Healthcare professionals (*n*=73)<br>Nurse (*n*=22), Medical (n=18), Not specified (*n*=33) | Not specified | - Challenges delivering care during COVID 19 – concerns about inability to deliver optimal care and the implications of this on patients' quality of life and survival<br>- Multidisciplinary team working and collaboration<br>- Psychological impact on staff well-being |
| **Rolland et al.** | 2021 | The Assistive Device Situation for ALS Patients in Norway | Norway | Qualitative semi-structured interviews<br>Systematic text-condensation analysis | Healthcare professionals (*n*=7)<br>Occupational Therapist (*n*=6)<br>Physiotherapist (*n*=1) | Community/ primary healthcare<br>Specialist ALS service | - Importance of anticipatory care<br>- Patient and family psychological adjustment<br>- Geographical variation in services<br>- Bureaucratic processes |
| **Casey et al.** | 2011 | Creating an Assistive Technology Clinic: The | USA | Qualitative case presentation | Healthcare professionals (*n*=1)<br>Occupational Therapist (*n*=1) | ALS specialist clinic | - Clinician knowledge<br>- Clinician confidence with assistive devices and technology |

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| | | Experience of the John Hopkins AT Clinic for Patients with ALS | | and clinical reflection | | | - Resources – funding for assistive devices, availability of devices<br>- Patent and family psychological adjustment<br>- Multidisciplinary team communication and collaboration |
| **Bakker et al.** | 2015 | Need and Value of Case Management in Multidisciplinary ALS Care: A Qualitative Study on the Perspectives of Patients, Spousal Caregivers and Professionals | The Netherlands | Qualitative semi-structured interviews and focus group<br>Inductive content analysis | Healthcare professionals (*n*=20)<br>Medical (*n*=9)<br>Case managers (*n*=2)<br>Speech and Language Therapist (*n*=1)<br>Psychologist (*n*=2)<br>Physiotherapist (*n*=2)<br>Occupational Therapist (*n*=2)<br>Social Worker (*n*=2) | Not specified | - Managing rate of disease progression<br>- Multidisciplinary team communication and collaboration<br>- Patient and family psychological adjustment<br>- Support provided by informal caregivers<br>- Time to provide adequate care |
| **Cutler.** | 2009 | The Experiences of Hospice Nurses who Care for People with Motor Neurone Disease. | United Kingdom | *Conference abstract<br>Qualitative semi-structured interviews with interpretative phenomenological analysis | Healthcare professionals (*n*=6)<br>Nursing (*n*=6) | Hospice | - Managing disease progression<br>- Challenges of motor neurone disease associated communication impairments<br>- Clinician knowledge and experience<br>- Multidisciplinary team communication and collaboration |

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| | | | | | | | - Experience of caring for patients with motor neurone disease identified as both '*challenging and very satisfying*' |
| **Brewah.** | 2019 | A Qualitative Study of the Preparedness of Practitioners to Care for People with Motor Neurone Disease in their Homes | United Kingdom | Qualitative | Not specified | Not specified | - Managing disease progression<br>- Anticipatory care<br>- Challenges with motor neurone disease associated communication impairments<br>- Multidisciplinary team communication and collaboration<br>- Clinician knowledge and experience<br>- Emotional involvement- emotional challenges and relationship building |
| **Ushikubo et al.** | 2012 | Circumstances Surrounding Death and Nursing Difficulties with End-of-Life Care for Individuals with ALS in Central Japan | Japan | Questionnaire<br>Descriptive design collecting brief quantitative data and qualitative responses to an open-ended question<br>Descriptive analysis and inductive content analysis. | Healthcare professionals (*n*=39)<br>Nursing (*n*=39) | Home care nursing | - Managing disease progression<br>- Time to provide adequate care<br>- Patient and family psychological adjustment<br>- Support required by informal caregivers<br>- Challenges with motor neurone disease associated communication impairments<br>- Ethical dilemmas - Balancing the needs of patients and informal caregivers, patient autonomy vs beneficence<br>- Multidisciplinary team communication and collaboration |

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| **Alquati et al.** | 2022 | Negotiating the Beginning of Care: A Grounded Theory Study of Health Services for Amyotrophic Lateral Sclerosis | Italy | Constructivist grounded theory method Semi-structured interviews employing theoretical sampling and constant comparison Conceptual coding data analysis | Healthcare professionals (*n*=12) Physical Therapist (*n*=1) Speech Therapist (*n*=1) Dietitian (*n*=1) Medical (*n*=5) Not Specified (*n*=4) | Hospital palliative care unit | - Importance of anticipatory care<br>- Individualised approach<br>- Patient and family psychological adjustment<br>- Engaging in difficult conversations | |
| **Hughes et al.** | 2005 | Living with Motor Neurone Disease: Lives, Experiences of Services and Suggestions for Change | United Kingdom | Exploratory and descriptive qualitative design Semi-structured interviews | Healthcare professionals (*n*=15) Nurses, other clinicians and managers, breakdown not reported. | Hospital Community Social care service | - Prioritised over other conditions<br>- Patient and family psychological adjustment<br>- Multidisciplinary team communication and collaboration | |
| **Cipolletta et al.** | 2021 | End-of-Life Care After the Legal Introduction of Advance Directives: A Qualitative Study Involving | Italy | Qualitative focus groups with thematic analysis | Healthcare professionals (*n*=24) Physicians (*n*=12) Nurses (*n*=7) Psychologists (*n*=5) | Community/primary care Hospital Amyotrophic Lateral Sclerosis Association | - Managing disease progression<br>- Patient and family psychological adjustment<br>- Engaging in difficult | |

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| | | | Healthcare Professionals and Family Caregivers of Patients with Amyotrophic Lateral Sclerosis | | | | | conversations<br>- Timing of conversations<br>- Time to provide adequate care<br>- Multidisciplinary team communication and collaboration<br>- Balancing the needs of patients and informal caregivers<br>- Emotional involvement – lack of preparation to deal with the emotive aspects of the communication process |
| **Hennessey** | 2016 | Neurologists Emotional Experiences in Caring for | USA | Qualitative Semi-structured interviews | Healthcare professionals (*n*=11) Medical (*n*=11) | ALS clinics | - | Emotional difficulty communicating a terminal diagnosis<br>- Frustration – lack of a cure |

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| | | Individuals with Amyotrophic Lateral Sclerosis: An Exploratory Study | | Grounded theory analysis influenced by Glaser and Strauss (1967) | | | - Timing of communication<br>- Managing patient and family emotion<br>- Support for informal caregivers<br>- Balancing the needs of patients and informal caregivers<br>- Clinician experience<br>- Multidisciplinary team communication and collaboration<br>- Organisational barriers – lack of time, services, financial obstacles<br>- Managing cognitive and behavioural changes<br>- Job satisfaction – rewarding experience<br>- Ability to make a difference<br>- Receiving gratitude<br>- Perspective<br>- Emotional involvement – emotional exhaustion, burden, burnout<br>- Coping strategies – compartmentalising |
| **Daneau et al.** | 2023 | Intensive palliative care': a qualitative study of issues related to nurses' care of | Canada | Qualitative semi-structured interviews content analysis method of | Healthcare professionals (*n*= 24)<br>Nurse (*n*=24) | Hospital<br>Hospice/ Palliative Care<br>Home Care | - Intensity of care – impacting ability to care for other patients<br>- Time to provide adequate care<br>- Challenges with motor neurone disease associated communication impairments<br>- Patient and family psychological adjustment |

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| | | people with amyotrophic lateral sclerosis at end-of-life | | Miles et al. (2020) | | | - Clinician experience<br>- Manging cognitive and behavioural changes<br>- Balancing the needs of patients and informal caregivers<br>- Engaging in difficult conversations<br>- Multidisciplinary team communication and collaboration<br>- Staff retention – 'exhausted care team'<br>- Rewarding nature of the work<br>- Emotional involvement – feelings of helplessness |
| **Beyermann et al.** | 2023 | Nurses' challenges when supporting the family of patients with ALS in specialized palliative home care: A qualitative study | Sweden | Qualitative explorative design<br>Interviews<br>qualitative content analysis according to Graneheim and Lundman (2017) | Healthcare professionals (*n*=11)<br>Nurse (*n*=11) | Specialised Palliative Home Care | - Individualised approach<br>- Collaboration with informal caregivers<br>- Balancing the needs of patients and informal caregivers<br>- Multidisciplinary team communication and collaboration<br>- Receiving gratitude<br>- Emotional involvement |
| **Kloos** | 2023 | Defining Moment: Searching for Answers | USA | Clinical reflection | Healthcare professionals (*n*=1)<br>Physiotherapist (*n*=1) | ALS centre of excellence | - Multidisciplinary team communication and collaboration<br>- Ability to make a difference |

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| | - Job satisfaction – personal and professional fulfilment |

## **Appendix E:** Focus Group Study: Letter of Ethical Approval

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

31st May 2023

**Re: Exploring healthcare professionals experiences of providing care for Motor Neurone Disease (MND) in Irish healthcare settings.**

Application No: REAMS 2551

Dear Ms. Walls,

Your application has been reviewed by the School of Medicine Research Ethics Committee (REC) and we are pleased to inform you that the above project has been approved.

Please note that documents submitted for GDPR purposes within your ethics application are approved by the REC from an ethical perspective only and this approval does not confirm GDPR compliance. Where a Data Protection Impact Assessment (DPIA) is required please submit the DPIA to the Data Protection Office (DPO) and seek comment from the DPO prior to commencing your study.

It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection Regulation (GDPR), Health Research Regulations and Data Protection Act 2018.

This Level 2 REC approval has been granted based on the information which you have outlined in your REC application and supporting documentation. You, and the named research team (if applicable), are responsible for conducting the research strictly in the manner outlined in your application and supporting documentation, and in compliance with it. Deviation from the study as outlined in the approved REC application will invalidate this REC approval. Any changes or amendments to the approved study must be re-submitted to the REC for approval in advance of any changes or amendments being implemented.

Yours sincerely,

Tadhg Stapleton,
Chairperson,
School of Medicine Research Ethics Committee,
Trinity College Dublin.

An tOllamh Coilin P O'Dochartaigh MD FRCPI FFSEM DQL
*Ceann Scoil an Leighis*

Dr. Alex McKee PhD
*Bainisteoir Scoile*

Scoil an Leighis
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Baile Átha Cliath,
Ollscoil Átha Cliath
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Dr. Alex McKee PhD
*School Manager*

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www.tcd.ie/medicine

## **Appendix F:** Focus Group Topic Guide

**Focus Group Topic Guide:**

- How would you describe your experience of working with patients with Motor Neuron Disease?
    - What words first come to mind?

- How would you describe your experience of supporting family caregivers of patients with Motor Neuron Disease?
    - What are the first words that come to mind?

- Have you ever felt unable to provide the level or type of care you wanted to provide for a patient with MND?
    - What were the barriers?
    - What helped you or would have helped you to provide the care you wanted to provide?
    - What resources would have helped?

- Have you ever found it difficult to provide support for a family member caring for somebody with MND?
    - What were the barriers?
    - What helped or would have helped or supported you?

- What do you find most challenging about working with MND?
    - Are there any clinical scenarios that you find particularly challenging to manage?
    - Are there are symptoms that you find particularly challenging to manage?
    - Do you find working with MND patients stressful?
    - If yes, what is it that you find stressful?
    - Do you find being exposed to MND emotionally difficult?
    - How does it impact you?
    - Do you find yourself thinking about patients outside of work?
    - How do you manage this? How do you separate work and home life?

- What do you find most rewarding about working with MND?
    - Do you work in a supportive team?
    - Do you see yourself staying in this role? why/why not?

- What characteristics do you think are helpful for professionals working with MND?
    - Are there any personal attributes that you or your colleagues have that you have found particularly helpful/unhelpful for this work?

## **Appendix G:** Documents Created to Support Online Focus Group Facilitation

### Guidance for Accessing an Online Focus Group via Microsoft Teams

- The meeting room can be accessed via the link provided and through a web browser however, the Microsoft Teams App typically provides a more stable experience. If you do not have the Microsoft Teams App installed on your device, we recommend installing this before you attend the focus group, and accessing the meeting link through the App.
- Microsoft Teams is available as both a mobile and desktop App.
- Microsoft Teams can be accessed using a desktop, laptop, tablet or smartphone. We ask that you choose a device with the best audio and video functionality and preferably a large screen (not a smartphone).
- Ensure your audio and video connections are correctly operating on the electronic device you intend to use beforehand – the research team are available to complete a trial if required.
- Ensure you have a stable and reliable internet connection.
- We ask that you enter the meeting room 10-15 minutes before the scheduled start time to troubleshoot any connection issues with the research team.
- If you experience any connection issues during the meeting, you can contact ……. At …… who will assist you where possible.
- We encourage you to use 'gallery' view on your screen rather than 'speaker' view during the discussion. Gallery view makes others visible on your screen and facilitates interaction among participants.
- We ask you to be mindful of your environment when participating in the focus group discussion. Where possible we ask that you choose a quiet and private space with minimal distraction.
- We ask that you mute your microphone when not speaking to reduce sound interference.
- If you have any questions about any of the above or wish to arrange a trial run, please contact the lead researcher Megan Walls on wallsme@tcd.ie.

## Key Roles and Responsibilities of the Focus Group Co-Facilitator

**Preparation:**

To familiarise self with the study materials provided by the lead researcher including the topic guide, objectives of the focus group discussion, the distress protocol, and data protection guidelines.

To familiarise self with the Microsoft Teams platform.

**Logistical and Technical Support:**

To admit all participants from the waiting room at the beginning of the group and any late commers after the group has started.

To support participants if they are having difficulty logging on at the beginning of the group or with their internet connectivity and readmitting people during the group if required.

To send a reminder email to participants who have not yet joined before the group is due to commence.

**Document field notes:**

To document field notes throughout the focus group discussion, that include:

A description of key external factors e.g., disruptions or excessive background noise that impacted on group discussion, disrupted internet connections, multiple late commers

Any group dynamics e.g., non-verbal cues that would not be picked up on an audio recording, group members that dominated the discussion or those who contributed little to the discussion, interactions between group members that potentially swayed the discussion.

The lead researcher's facilitation skills - leading questions or other verbal or non-verbal responses made by the facilitator that may have influenced, impacted or guided the participants to answer in a certain way.

**Implement the distress protocol if required:**

To be vigilant of participants who are demonstrating any signs of emotional distress or discomfort as indicated in the distress protocol and to implement the protocol if required.

**Time keeping:**

To be mindful of the time allocated for the focus group discussion and to prompt the lead researcher if the discussion is running overtime.

**De-briefing:**

To de-brief with the lead researcher after the group. To help identify key insights from the discussion, provide feedback on the facilitator's moderation skills and any recommended any changes for future groups in relation to group facilitation or organisation.

**Data validation:**

To review pseudo-anonymised transcripts after they have been cleaned by the lead researcher to verify that the transcript accurately reflects the focus group discussion and to highlight any potential errors to the lead researcher.

## **Appendix H**: Detailed Reflexive Thematic Analysis Process Log

### Data Analysis Process Log

**Phase 1: Familiarisation**

1. All focus groups were transcribed and verified against the original video recordings to ensure accuracy. The transcripts were read and re-read by the lead researcher to support familiarisation with the data. During this process, initial reflections were documented for each focus group, noting key points, emerging ideas, and early patterns of interest. A reflexive journal was maintained throughout, capturing the researcher's personal reflections on facilitation style, the perceived influence on group dynamics, and any logistical or operational issues encountered during the sessions.
2. Once all focus groups were completed, the transcripts were revisited with comments inserted by the lead researcher to support the development of initial codes. These comments captured both the explicit content shared by participants ‘Form a strong relationship due to frequency and intensity of intervention’, ‘An illness that also has an impact on the health and well-being of family members’ and what the researcher interpreted the text as meaning e.g. ‘Anticipatory stress - fear of not having something available for a patient if they need it in the future’, ‘Balancing planning for future care needs, in a timely manner so that opportunities aren't missed while allowing adequate time for psychological adjustment’.
3. Each transcript was read twice, with the second reading allowing for additional observations and the integration of insights that had emerged during reflection and the analysis of earlier transcripts. The ‘initial thoughts’ documents were reviewed at this point and ‘new thoughts and ideas’ were acknowledged and documented for each of the transcripts.

**Phase two: Coding**

1. NVivo 12 was used for the first round of coding. Transcripts were coded individually and grouped according to service type, beginning with the three multidisciplinary clinic teams. MND specific services, where the majority of participants caseload comprised plwMND, were coded first, followed by non-MND specific services, where MND cases were less frequent (typically two to three patients per month). During coding, previously recorded comments on the transcripts were revisited to ensure that earlier reflections and interpretations were integrated and not overlooked.
2. After coding the first five transcripts from the specialist services, an initial review of the generated codes was undertaken. Several overlapping codes were merged to better reflect the content and reduce redundancy. For instance, ‘learning experience’ and ‘motivation to learn’ were combined into ‘learning experience, motivation to learn and enhance clinical skills’, while ‘self-awareness’ and ‘emotional intelligence’ were merged into ‘emotional intelligence and self-awareness’. Twelve codes that initially appeared in only one transcript were reviewed to assess whether they overlapped with existing codes or were uniquely tied to specific services. Following this review, only three of these codes remained as singular occurrences, deemed unique to their respective transcripts.

3. The first five transcripts were then re-coded using the refined coding framework. This allowed for integration of ideas that had emerged during later stages of the coding process, ensuring consistency and completeness.
4. The final four transcripts, representing 'non-MND specific' services (in which people with MND comprised less than 25% of the caseload), were coded together. This stage involved iterative review and ongoing refinement of the coding framework. As new ideas emerged, new codes were generated, such as 'communication – ensuring autonomy', 'Difficult conversations at end of life', 'variability in presentation', and 'intensity of care required'.
5. Once all nine transcripts had been coded, a comprehensive review of all codes and the associated text was conducted. Code names were revised where necessary to improve clarity and alignment with the content. For example, 'Questioning professional integrity or effectiveness' was renamed 'Feelings of professional ineffectiveness or inadequacy'; 'Avoidance vs experience' was revised to 'Experience vs inexperience'; and 'Anticipatory stress – changing nature of the condition – uncertain trajectory' became 'Anticipatory stress – working with uncertainty'.
6. Finally, the earlier transcripts were reviewed once more, this time with a focus on identifying any examples of the new codes developed later in the process. Particular attention was given to codes that were newly created or that had only appeared in a small number of transcripts, to determine their broader relevance across both specialist and non-specialist services.

**Phase Three: Generating Themes**

1. Following the completion of the coding process, the first thematic map was constructed, with individual codes grouped to generate aggregated meanings around central concepts, forming initial candidate themes. All codes and their associated data extracts were then transferred into Microsoft Excel. Separate tabs were created for each of the emerging candidate themes, alongside additional tabs for miscellaneous codes that did not clearly align with any initial theme.
2. At this stage, the primary candidate themes included: *The Relationship*, *Working with Uncertainty*, *Sitting with It*, *Unable to Provide Any Solution*, and *Personal Toll*. Additional tabs were created for: *Helpful Factors* (capturing explicit protective factors described by participants), *Intensive Care* (relating to the nature and complexity of care), *Comparisons* (data contrasting different participant groups, such as those intending to leave vs. remain in their roles, and differences between specialist and non-specialist services), and *Miscellaneous* (codes not yet fitting within any theme).
3. Each candidate theme was then systematically reviewed to explore the interrelationships among the included codes and to construct a coherent narrative around the central idea. Key text segments and particularly powerful or illustrative quotes were highlighted and examined in terms of their contribution to the thematic development.
4. To support this analytical phase, mind maps were created for each candidate theme, helping to refine the thematic structure and logical flow, and ensuring that supporting data aligned with the thematic content. Multiple potential names were considered for each theme to capture their essence more accurately and reflect the underlying meaning of the data.

**Phase Four: Reviewing Potential Themes**

1. In this phase, the researcher engaged in a recursive and critical review of the identified candidate themes and sub-themes. This involved a systematic re-examination of all coded data items, with close attention to the relationships between individual codes within each subtheme, and between subthemes and their overarching theme, to ensure that each theme was internally coherent and centred around a core conceptual idea. The raw data were revisited throughout this process to confirm that key points and significant data extracts had been appropriately captured, and that no important material had been overlooked.
2. The researcher also assessed the developing themes against the full dataset to verify their representativeness of the participants' core ideas and experiences. Themes were evaluated in relation to the objectives of the study to ensure that the final thematic structure provided a comprehensive and meaningful response to the study's aims.
3. This was a recursive and iterative process, requiring the researcher to move back and forth between the raw transcripts, coded data, initial analyses, the reflexive journal, and the research objectives. The goal was to refine and clarify the thematic framework to best reflect the most salient and significant findings in the data.
4. To guide this process, Braun and Clarke's (2019, p.65) set of evaluative questions were employed:

    - Is this a theme, or merely a code?
    - If it is a theme, what is the quality of the theme (i.e. does it offer a meaningful insight into the data and research question)?
    - What are the boundaries of the theme (what does it include and exclude)?
    - Is there sufficient meaningful data to support the theme (is it thick or thin)?
    - Are the data within the theme too diverse or lacking coherence?

    These guiding questions supported the development of rich, well-defined, and analytically robust themes that both accurately reflected participants' experiences and aligned with the objectives of the study.

**Phase Five: Defining and Naming Themes**

1. In this phase, the researcher developed a detailed analysis of the thematic framework. A final thematic map (Figure 4.1) was constructed to visually represent the relationships between themes and sub-themes, and each theme was written up in depth, drawing on both the full dataset and the overarching research questions. Braun and Clarke (2024) emphasise that themes should connect in a logical and meaningful manner, creating a coherent and condensed narrative of the data. Each theme should not only build upon the ones that precede it, where conceptually appropriate, but also maintain internal consistency and be capable of standing alone as a distinct narrative, even when isolated from the broader analysis.
2. The final four themes presented in this study represent distinct yet interconnected dimensions of healthcare professionals' experiences throughout the MND care journey.
3. At this stage, supporting participant quotations were also carefully reviewed to ensure that the most illustrative and analytically powerful extracts were selected.

Quotations that were insightful but not essential to the primary narrative, such as those that duplicated sentiments, were removed from the body of the analysis and included in a supplementary table of additional quotations (Appendix J).

4. Particular attention was also paid to the naming of themes and sub-themes. Potential names developed during earlier analytic stages were revisited and critically considered in line with Braun and Clarke's (2024) recommendations, which suggest using names that are clear, engaging, and capable of capturing both the reader's attention and the essence of the theme. In some cases, direct excerpts from participant data were used as thematic titles or sub-headings to more vividly evoke the content.

**Phase Six: Producing the Report**

1. As Braun and Clarke (2012) recognise the write-up of qualitative research is very much interwoven into the entire process of the analysis. However, this phase involved bringing together each aspect of the research process into a condensed and coherent report. The Reflexive Thematic Analysis Reporting Guidelines (Appendix I) were followed to support accurate and rigorous reporting, ensuring alignment with the philosophical and methodological underpinnings of RTA.

## **Appendix I:** Reflexive Thematic Analysis Reporting Guideline (RTARG)

| **Advice for aspects of the research report/approach to reporting** | **Guiding notes and further explanation** | **Practices, concepts and terminology to avoid** | **Addressed in section/page number** |
|---|---|---|---|
| **The Introduction**<br>NB: We prefer *Introduction* over *Literature Review* as a section heading, to capture the broader purpose of this section. | | | |
| ***Background and rationale*** | | | |
| Provide a robust context and rationale for the proposed research in the *Introduction*. | Can discuss existing research, theory, and the wider context; the researcher is understood as *entering a conversation* with existing scholarship. | Critiquing the methodological limitations of existing research from a (post)positivist/ quantitative standpoint; orienting a literature review to finding a "gap" that the research fills. | 4.1 Introduction<br>p.73-75 |
| Clearly articulate a research question – one that is methodologically coherent. | Can discuss refining an initially broader research question to a more specific one for the paper. | Formulating research questions as hypotheses or expectations about what might be "found". | Introduction section 4.1.<br>p.75 |
| ***"Owning your perspectives"*** | | | |
| Include information on guiding theoretical assumptions and other (e.g., explanatory) theory informing the use of TA. | Guiding (e.g., paradigmatic, ontological and epistemological) and other | (Post)positivism and (simple) realism. | Methodology section 4.2.<br>p.75 |
| Report in a way that is consistent with stated theoretical assumptions throughout. | Theoretical coherence is evidenced through the use of language and concepts (e.g., around theme development, research subjectivity, data interpretation), the treatment of data, and use of quality practices consistent with RTA. | Inadvertently "mashing-up" of RTA and (post)positivism/ realism (e.g., assuming data interpretation can be accurate and reliable) – without a clear rationale. | The theoretical position is explicitly stated at the outset of the chapter and the research design, analytic approach, language used, and interpretation of findings consistently reflect and align with those assumptions and RTA principles. |

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| Evidence methodological coherence/integrity in both the research and the report. | Theoretical assumptions, research questions, methods/practices of data generation, RTA, and specific orientation to RTA, purpose of research etc. all "fit together", conceptually. | Ontological and epistemological confusion (e.g., claiming constructionism but focusing on lived experience and treating language as a transparent window onto this). | As above. |
| Show evidence of reflexive practice. | Can discuss researcher professional or personal positioning and experience in relation to the topic, and/or participant group, and/or their role in shaping the research; use of reflexive journaling. | Evoking researcher bias (positivist), or even researcher influence, in a way that evokes it as possible rather than inevitable. | Data Analysis 4.2.3 – Researchers position and Reflexivity, p.84-86 |
| Write in a methodologically coherent style. | A first-person writing style suits RTA, as it "writes in" the researcher and contributes to situated and reflexive reporting. | A third person writing style – writing the researcher out of the research. | A first-person writing style was not used to maintain consistency with the remainder of the thesis chapters. |
| **The Methodology**<br>NB: We prefer the theoretically-embedded term *Methodology* as a section header, over the proceduralist term *Method*. | | | |
| | ***Participants/data items*** | | |
| Describe selection of participants/data items. | Should include criteria for selection and/or recruitment strategies and settings. | Terms "sample/sampling", which connote "sampling" from a population (for the purpose of statistical generalisation). | 4.2.1 Sampling and Recruitment p.76 |
| Describe number of participants/data items; provide a rationale or explanation around dataset or participant group size/composition. | Non-positivist qualitative concepts, such as "information power" or sufficiency offer conceptually appropriate justifications for "dataset" or "participant group" size and composition. | Justification based on saturation (simple realist), or statistical models (positivist); reporting rates of non-participation (an indicator of the representativeness of the "sample" in quantitative research). | 4.2.1 Sampling and Recruitment p.77-78 |

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| Discuss characteristics of participants/data items. | Balance the need to "situate the participant group" with participant anonymity (e.g., aggregate or report minimal demographics where appropriate). | Tables with each participant's demographic information listed line-by-line. | 4.3.1 Participants<br>p.79 |
| ethical code/principles followed, participant informed consent, etc. | Ethical discussion usually includes institutional ethical approval (if needed), but may include wider principles; providing research materials (participant information, consent form, etc.) in supplementary materials may be useful to support reflexive openness. | Compromising participant anonymity by the details provided. | Methodology – Ethical approval & data protection, p.76<br><br>Appendix E – Letter of Ethical Approval, p.368 |
| ***Dataset generation***<br>NB: We prefer the term *generation* over *collection* to capture the active role of the researcher and that data don't pre-exist research *as* data but *become* data through research practices. | | | |
| Provide some rationale for method(s) for data generation/data item sources chosen. | Discuss why the method(s) of data generation/data source was a good fit with the research question, participant group, guiding theory, etc. If multiple data sources are used, any rationale for combination should be conceptually appropriate (e.g., crystallisation). | Triangulation as a rationale for different data sources (realist). | 4.2.2 Dataset Generation – Rationale for focus group method<br>p.79 |
| Describe development and/or characteristics of data generation tool(s). | Include tool(s) in supplementary materials when possible; discuss piloting if used, and any changes following piloting, or during data generation. | Using an existing tool with the aim of replicating existing "findings", or developing and describing a tool in a way that is intended to facilitate future replication (positivist). | Appendix F – Focus group topic guide, p.369<br>4.2.2. Topic Guide and Question Development, p.80 |

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| Include details such as modality and/or setting of data generation, time frame, and other pertinent procedural information. | Relevant information includes: the mode of a data generation tool (e.g., video call focus groups; chat-based interviews); the context of data generation (location; timeframe) – where this doesn't compromise participant anonymity; and mode of recording interactive data generation. | Standardisation as a gold standard (realist); justifying an aimed for standardisation in data generation tools as a means to facilitate the "reliability" or "accuracy" of the research; treating a lack of standardisation in data generation method, modality or setting as a problem, a potential source of "bias". | 4.2.2 Focus group facilitation p.81 |
| Describe who conducted any interactive data generation (which author or research role), and how. | Can include what, if anything, the researcher disclosed about their personal or professional positioning or motivation; what skills and experience they brought; note researcher's relationship with participants prior to, during and after the research. | Seeking standardisation (e.g., through the training of researchers) in interactive data collection; treating non-standardisation as a threat to "reliability" or "accuracy". | 4.2.2 Focus group facilitation p.81 |
| Describe the size/scope of dataset and dataset items. | Such as the range and average length for interviews/focus groups; range and average word length for textual items. | Equating data *quantity* with data *quality*. | Sample size determination p.77-78 |
| Describe, and if relevant explain, any preparation of data for analysis. | Such as method of transcription of audio/video data (a transcription key can go in supplementary materials); changes and "corrections" – such as why typographical errors in written data were corrected; system for removing any identifying information; use of pseudonyms and/or data codes. | Describing transcription as "verbatim" or "orthographic" with no further details; using edited or "cleaned up" data without acknowledgement of this; participant validation of the "accuracy" of transcripts (realist). | 4.2.3 Data analysis – transcription and data management, p.82 |

| ***Data analysis*** | | | |
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| Provide some rationale for use of RTA, and, where relevant, for combining RTA with other approaches and procedures. | Any combining of RTA with other method/ologies or procedures should be warranted, rather than based on a misunderstanding of RTA, and conceptually coherent (unless clearly justified). | Citing generic characteristics of RTA (e.g., accessible, flexible) without explaining how they were *relevant* to the study; using a codebook without acknowledging this is not part of RTA and justifying its use. | 4.2.3 Data analysis – reflexive thematic analysis, p. 82. |
| Describe specific orientation to RTA. | Locate RTA on dimensions of inductive<>deductive and semantic<>latent. | A generic discussion of TA (or even RTA), not specifically situated in relation to the study or approach. | Table 4.2 – reflexive thematic analysis process, p.83. |
| Discuss how the researcher(s) engaged with the analytic process. | Provide a specific and situated account of the analysis process; use supplementary materials to provide a fuller account of the analytic process. | Offering a generic description of the six phases of RTA in lieu of an account of analytic process. | Appendix H – Detailed data analysis process, p.372-375 |
| Where more than one person is involved, describe who analysed the data (author or research role). | Role(s) or involvement throughout the process should be discussed; where coding was collaborative, what this involved and how differences in coding and theme development were tackled, should be included. | Use of inter-coder agreement measures, consensus coding approach (positivist). | 4.2.3 Data analysis – Reflexivity – The data analysis was completed by the lead researcher (MW), the supervisory team were involved in questioning insights, reviewing and commenting on the analysis generated.<br>Table 4.2 reflexive thematic analysis process, p.83. |
| Use language to describe the process and products of RTA that is coherent with the values and assumptions of RTA. | Language should convey the *active* role of the researcher(s) in "generating", "crafting", "constructing", "creating", "producing" or "developing" themes; language around | Passive language of discovery, such as "emerging", "found", "identified", "discovered" – these evoke themes as "diamonds scattered in the sand" (p. 740)10; unexplained | Appropriate language used when describing data analysis process (4.2.3) and in the reporting of results (4.3). |

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| | themes should evokes them as *products* of a researcher-data process. | use of language and concepts from other approaches, such as emergent or superordinate themes (IPA), or line-by-line and/or open coding and constant comparison (grounded theory). | |
| **The Analysis**<br>NB: We prefer the heading *Analysis* over *Findings*/*Results*. *Findings* implies the researcher "found", "discovered" or "identified" pre-existing themes. *Results* is strongly associated with the outputs of statistical analysis. | | | |
| ***Reporting the data analysis*** | | | |
| Provide an overview of themes or thematic structure. | Overviews can include a list, map or table of themes to preview the analysis. | An unclear thematic structure, including unexplained headings in the *Analysis*. | Figure 4.1 - Thematic map, p.122 |
| Ensure theme conceptualisation is appropriate to RTA, and any divergences are justified and explained. | In RTA, themes report shared meaning, united around a central organising concept that differs for each theme. | Topic summaries; data generation questions reported as "themes". | Each theme presented in the analysis centres around a central organising concept and each theme is conceptually distinct. See phase three and four in Appendix H above for a detailed description of theme development, p. 372-375. |
| Name themes appropriately. | Use theme names that capture the "essence" or "story" of each themes; brief data quotations can be used. | (One-word) theme names that only identify a topic, and offer no story (evoking topic summaries). | Table 4.2 – point 5 - Theme names were carefully reviewed to ensure they not only captured the essence of the data but also engaged the reader's attention and clearly conveyed the central ideas within each theme and its sub-themes, p. 83. |

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| Report themes in sufficient depth and detail. | As RTA is an interpretative method, themes should be multifaceted, and contain both data and analytic narrative; if useful, additional data extracts may be included in supplementary materials. | Thin, one dimensional themes, effectively conflating codes and themes; large number of themes relative to the length of the manuscript. | Additional data extracts provided in Appendix J – p.385-389. Themes are multifaceted, rich and analytic in nature. |
| Use subtheme judiciously. | Themes are the main analytic purpose and should be multifaceted; only use subthemes where doing so highlights an important facet or aspect of the central concept of a theme. | Fragmenting the analysis through overuse of subthemes, and an overly elaborated/"bitty" thematic structure. | The four themes constitute the main analytic structure of the findings. Sub-themes were used to organise data within each theme and to support readability, given the depth and richness of the thematic analysis. |
| Ensure the analytic narrative explains the meaning and significance of the data. | For RTA, each theme needs an analytic narrative that outlines its meaning and importance in relation to the topic, research question and dataset; the reader needs to be told about why/how data excerpts matter and "evidence" the theme; the A*nalysis* section also needs to convey the *overall* story of the analysis. | Frequency counts as a justification for themes presented; simple paraphrasing of data as "analytic narrative"; treating data meaning as self-evident (data are assumed to speak for themselves); "arguing" with the data (treating the data as something to [dis]agree with, rather than to interpret and make sense of). | The 'overall story' is outlined at the outset of the analysis section, p.87. |
| Provide an appropriate *balance* of analytic narrative and data extracts – both data extracts *and* analytic narrative matter. | The rich descriptive and/or interpretative story of the analysis needs to be woven around sufficient analytic extracts from across the dataset. | Presenting either a long string of data extracts with barely any analytic narrative, or *only* the researcher's narrative summary of the theme, without any data extracts to support it. | Analytic extracts are included throughout the results section – additional supporting quotations provided in Appendix J, p.385–389. |

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| Demonstrate coherence between analytic narrative and illustrative/evidentiary data extracts. | Data extracts should convincingly and compellingly evidence the analytic claims. | Mismatches between data extracts and analytic claims; not countering obvious alternative readings of the data | Themes reviewed by the supervisory team to ensure coherence between narrative text and data extracts. |
| Integrate existing research and theory into the analytic narrative. | In RTA, an interpretative analytic narrative is enriched by incorporating relevant existing research and theory into the reporting of themes, reflecting notions of contextualised meaning, and contributing to an ongoing "conversation" about a topic. | The positivist tradition of separating a description of analytic "Results" and their interpretation with reference to scholarship and theory in a "Discussion" section. | This is addressed in the discussion section of this chapter, again to maintain consistency with the structure of this thesis. |
| **The Final Section – A General Discussion or "Conclusions"**<br>NB: We don't have a preference for what a final section of an RTA report is called, and it depends on the context and the focus and purpose of the study – the heading *Conclusion* may evoke a certainty that isn't appropriate; *Implications* may be useful; *Final Considerations* or *Reflections* may work, as might *General Discussion*. | | | |
| ***Quality, evaluation and conclusions*** | | | |
| Draw analytic conclusions across themes. | Orient to the "so what" of the *overall* analysis – the "point" of the story told; this might include discussion of implications for practice and "actionable" outcomes. | Repetitive theme-by-theme integration of the analysis with existing literature; no overall conclusions drawn; no overall analytic story. | Addressed in the discussion section 4.4 – multiple suggestions for future work and considerations for practice addressed. p. 123-143. |
| Discuss implications or directions for future research. | Any suggestions for future research should stem from the analysis and be evidence-based (e.g., provide grounds for other groups potentially having different experiences or views) rather than generic. | Generic recommendations for other research, such as with a different "population". | Addressed throughout discussion section 4.4, p.123-143. |

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| Use and report quality practices coherent with RTA. | Ensure evaluation of research quality deploys conceptually coherent notions, such as: member reflections; crystallisation; others serving as a critical friend/sounding board to enhance insight; reflexive journaling. | Incoherent quality measures such as: member checking/participant validation; triangulation (realist); the use of theme agreement/consensus among researchers or corroboration of themes by another researcher (positivist). | Acknowledged in section 4.4 study strengths and limitations, p. 142-143. |
| Evaluate the research from a *Big Q* standpoint. | Such evaluation might include considering how the *specifics* of the study may have shaped the research produced (for example, the characteristics and context of the participant group/dataset; the methods and modalities for generating the data); situatedness should not be treated as a limitation. | Evaluations and descriptions of limitations that orient to quantitative or positivist norms, such as reference to lack of generalisability – positioned as a limitation, and equated only with statistical generalisability – or a "small" (by implication non-ideal) and "unrepresentative" "sample". | Addressed in section 4.4 study strengths and limitations, 142 – 143. |
| Include reflections on research process and practices, including researcher reflexivity. | Some consideration of the researcher(s)'s role in shaping the research and the knowledge generated is an important quality marker. | Reference to researcher bias/influence (positivist). | The active role of the lead researcher is addressed in section 4.4 study strengths and limitations, p.142-143. |

This reporting guideline is from: Braun V, Clarke V. Supporting best practice in reflexive thematic analysis reporting in Palliative Medicine: A review of published research and introduction to the Reflexive Thematic Analysis Reporting Guidelines (RTARG). Palliative Medicine. 2024;00(0):1-9. https://doi.org/10.1177/02692163241234800.

## **Appendix J:** Additional Supporting Quotes

| **1.1 The Depth of the Relationship** |
|---|
| *…that kind of sense of you're really going to get to know this person and the people involved with them and their family and yeah, it's going to be quite a significant relationship…it's that kind of from the start, until they more than likely pass away, you're going to be involved… like from the moment you open a client with motor neuron, they're never discharged, ever you know.* (OT, Primary Care) |
| *But like if you develop a relationship with someone, a therapeutic relationship with someone and… you're seeing them fortnightly regularly for a couple of months and then they just pass away or they're too unwell to come back and you never see them again, that for me is just really sad.* (Psychologist, Multidisciplinary Clinic) |
| *You're involved in a family in the worst moment of their life, and they've welcomed you in and they're accepting you in and they're willing to take your help and I think that's a complete privilege.* (OT, Primary Care) |
| **1.2 Personal Resonance and Emotional Connections** |
| *They're, definitely like, the cohort that I go home and think about… like if you have a tough day and you get in your car, you kinda have a moment like, thank God I can drive my car…like how awful would it be, to not be able to scratch your face?* (Nurse, Palliative Care) |
| *Like back over the years, there's been quite often a point where like I think I would love to send a card or I'd love to put up a condolence and then I was like, you know what, you know, if you start where do you stop…* (Dietitian, Multidisciplinary Clinic) |
| **1.3 Trust and Boundaries** |
| *Sometimes certain professionals like Physio or OT for example, can be brought in almost to break the bad news that we have to transition from one type of hoist say to another, and sometimes that does leave one person vulnerable to being the one who gets naturally the brunt of the negative emotion or being blamed for, well, it was your decision as opposed to its what's safe and necessary at this time, and obviously there's a lot of grief and a lot of stress for the person when they acknowledge that this is, or they don't want to acknowledge that this is a progression of the disease… so, it becomes [the healthcare professional] was the problem as opposed to the message. You know it becomes more personalised than it needs to be*. (PT, Residential Care) |
| *A big part of this job is managing people's expectations, and part of that is maintaining our own integrity, because sometimes you can get a little bit carried away and sidelined with some families, particularly where there's dynamics, but I think it's very important that we're very cognisant of working within our own scope, particularly because we're lone workers and it is about maintaining our own integrity within that.* (Nurse, Charity Organisation) |
| **2.1 Anticipatory Stress** |
| *So, in my experience anyway, I think it can depend, but I think definitely there's nearly when you hear there's a patient coming in with MND as much as you don't want to, you kind of initially kind of have a thought, you know, feel a little bit anxious or stressed about that patient coming in as an inpatient or outpatient.* (OT, Palliative Care) |

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| *I would echo some of that as in there's a sense of, there's kind of an anxiety and worry about it [An MND patient being admitted to an Inpatient Palliative Care Unit]. So, my questions are… how far is this person along the road in terms of communication and communication aids, so all of that piece comes up for me just around how am I going to communicate with this person?* (MSW, Palliative Care) |
| *Almost like foreboding stress, if you see referral come in, you're like ohh, hopefully I can deal with this, you know…* (OT, Residential Care) |
| **2.2 Working with Uncertainty** |
| *…but with MND it's much harder to kind of predict at times what that's going to look like and trying to support people around the care distress and the emotional distress as well… I would see that people, family members often require an awful lot more support, and that can be difficult to kind of plan around expectations and what to expect because there's so much of the unknown involved.* (Medical Social Worker, Palliative Care) |
| *…and like I would meet a lot of people after diagnosis and, you know, it depends where they're at and how much they've actually taken on board, how much they know already about the diagnosis, whether you can, you know, actually go there with the prognosis and the care that is available to them, such as, you know, the different… the NIV or a PEG or anything, often they're not able to hear any of that earlier on because they're still overwhelmed by the gravity of the diagnosis.* (Nurse, Charity Organisation) |
| *Sometimes in terms of like you're trying to prepare for the future, say things like voice banking… you don't want to miss the boat, but at the same time you don't want be like the big, bad pessimistic wolf saying I think you have to start voice banking even though you're fine now, and like sometimes people aren't ready for everything but you still don't want them to miss the boat so getting that balance, I find hard sometimes. You are kinda trying to be negative and positive at the same time.* (OT, Palliative Care) |
| *That's it exactly, and should we make the housing adaptations? Yeah… and the answer is well no, because by the time it's done, the person won't benefit from it… and again, that's probably a systems thing because it takes so long, if they're going to go down the grant option and looking for funding, you know, by the time it's done… they're going to be requiring greater care.* (OT, Multidisciplinary Clinic) |
| *It's getting the timeliness of assessment and future proofing it in a way that you're going to be able to facilitate them independently mobilising it's almost impossible, and then that goal becomes really important for people when they come off their feet and then it's too late because, you know, as a therapist, that from a prognosis perspective, you're unlikely to get a power chair in place… you know, it's really, really difficult'* (OT, Specialist Seating and Technology Service) |
| **2.3 Communication** |
| *I think you need to be a good communicator not only with family but also with healthcare professionals also involved with the care and realise that there's not one person that's gonna be the fixer of everything, or the controller of everything, and that no one person is the most important person in the team. Everybody has their own role and function, so everybody brings something, so for us to remember that we're one part of the cog of the wheel, and to work within this area and look after somebody with MND that, you have to be good at communicating with other healthcare professionals about what your plan is… in terms of like your point of care, whether you're a nurse, an OT or a physio, but also that it fits in with* |

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| *the rest of the plan of care that everybody else has as well. So being good at communicating that too.'* (Nurse, Charity Organisation) |
| I've had people with motor neuron disease die and nobody's ever told me. ...because the communication is so bad, and then by accident, I'd ring to check in with somebody and the person has died, you know? And so the communication is like horrific. (Dietitian, Primary Care) |
| **2.4 Managing uncertainty** |
| *There is no point going in saying you have to do this, you have to that, you should do this. You know that that doesn't work... it has to come from them and it's just, I suppose, being able to frame the information... in such a way that they have the control over the different choices they can make around their care.* (Nurse, Charity Organisation) |
| T*hat gentleman, (OT) with his coat rack, yeah, you don't even want to know, kind of thing... and you have to let go of your own, I don't know barriers or worries or stresses and let them let them be and make their choices.* (Speech and Language Therapist, Multidisciplinary Clinic) |
| **3.1 Helplessness** |
| T*he barrier was that the source of the problem was within another organisation, and I would feel that I kind of had good links with that organisation... but at the same time, you can't control their workflows* (Speech and Language Therapist, Multidisciplinary Clinic). |
| *But I think what's a huge challenge with our patients with MND, despite your very best efforts, despite, you know, rallying the troops, to get all community services in place, organising with the PHN (Public Health Nurse) to get a really good home care package and fighting to get the best amount of hours, and getting the volunteer service in and you know, literally going to every length for every person, the situation is still the situation... we can't fix the reality of the situation, you know? (Nurse, Palliative Care).* |
| *...we were seeing a team around, this patient who is becoming very burnt out as well because there was no real kind of tangible way to support her, so it was just, it was very It was very difficult... and I don't know that there was any real answer, but as a team it took a toll, definitely, because you're witnessing somebody who is struggling and suffering without necessarily being able to do anything to support somebody. (MSW, Palliative Care)* |
| **3.2 The difficult but important job of '*being there*'** |
| *I've had one or two people and they might just cry for the entire half hour, and you come away and you're a bit like, kind of feel like, I did nothing there, they just cried for half an hour, but then they leave and they say like I feel so much better for having done that, so you kinda think like well, I'm getting some sort of positive feedback, you know, I don't know what I'm going to put my note now because I didn't really do anything, but yeah.* (OT, Palliative Care) |
| *So sometimes I just think if you can just bring a bit of just sitting with somebody holding them in that space without having to make it better or try to fix it and you know it's it feels very helpless when you're doing that, but I think that that* |

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| *can be helpful, and you know, we don't need to tell anyone how to feel, they're going through that.*(Medical Social Worker, Palliative Care) |
| *I find that very difficult, not to necessarily intervene and just allow the patient to talk, but I think it's a very important attribute*. (Nurse, Charity Organisation) |
| *I suppose experience gives you the confidence to go into a house now with your hands beside, down at your side you know that you're not carrying in a suitcase of forms and assessments. You know that you have that experience and confidence*. (OT, Primary Care) |
| ***3.3 – Positive Reframing – Finding meaning and purpose*** |
| *So, I think it's really refocusing your thought process on being there and being a listening ear and the bits that you can do can be enough, you know, rather than actually changing things dramatically or changing the course of it, So being comfortable with knowing that, but it's, while you're not going in with a big bag of things that are going to dramatically change the outlook or the progression that still actually being on the journey with them is a significant role, you know.* (Nurse, Multidisciplinary Clinic) |
| *...we know where it's going, we know they're going to die from this condition. We don't know how long it will take, but if we're there along the journey, we can actually provide a good life for them and they're living well with this condition as much as is reasonable, and much as is possible, I think that can be very rewarding as well.* (Nurse, Charity Organisation) |
| **4.1 It takes a personal toll** |
| *Another OT who started since I've started, you know, told me how upset, how upset she was driving home from appointments and how tough she found it and how she was so surprised that there were no structures in place for that.* (OT, Specialist Seating and Technology Service) |
| *But I do think it's very yeah, it's very emotionally draining, very difficult, like very sad. So yeah, you do have to mind yourself, definitely in this*. (Nurse, Charity Organisation) |
| *Here it's, It's so sad, like it's just absolutely so sad. I mean I I find it very sad. Before I started this job, you know, I use cry at a film or and things like that, but Oh my God, I, you know, I I said to my friend, I can actually cry now without crying. Like certainly at most, it does have an emotional impact.* (Nurse, Charity Organisation) |
| *I suppose when I guess a referral for somebody with motor neurone disease, my first feeling is sort of sadness that oh, I think this is a terrible diagnosis for somebody to get and I feel that the person with the motor neurone disease has a sort of an uncertain and a sort of troubling road ahead of them.* (Dietitian, Primary Care) |
| *4.2* ***Helpful and Supportive Factors*** |
| *So being very mindful at one time, what do I need to take care of myself and how do I need to prepare myself. Uh, Im not just gonna override my stress, you know, I'm going to acknowledge, OK, this is difficult*. (Nurse, Palliative Care) |
| *Just to reflect on what went well, what was difficult and how do we feel about it, you know, when it's safe kind of context because it is a really emotionally very, very difficult and challenging and you know we can acknowledge that for the patient themselves its, so tough and for family. But it does have an impact on the team.* (MSW, Palliative Care) |

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| *We also get a lot of support from each other, although it might not be hugely formal, there is a lot of support we get from eachother.* (Nurse Multidisciplinary Clinic) |
| **4.3 Sustaining Factors** |
| *It is the thing and I would say, you know, we definitely do in those situations where we get to get things in place in time even when the person passes that we do get that kind of, you know, people send mass cards or that… and you know that you've done your best you know, it's very it's incredibly rewarding***.** (OT, Specialist Seating and Assistive Technology Service) |
| *You know you can learn so much and… like it challenges you to be better, as like if somebody cannot tell you where they're uncomfortable or… literally, they're blinking as you're pointing at letters, you know, it really is challenging, but equally, when you get it right and when you walk away, having helped the person, you do feel better as a person*. (Complimentary Therapist, Palliative Care) |
| *I'm interested, so I would always like to have maybe one or two patients on my caseload that have a diagnosis of MND because I think from an Occupational Therapy perspective, we have such a broad scope of practice with them depending on what stage they are in their journey. And I think it can be really good learning and we can make a difference in terms of equipment provision and quality of life.* (OT, Residential Care) |

## **Appendix K:** Additional Qualitative Analysis

| **Differences between Individual Services** | |
|---|---|
| **Specialist Palliative Care** | • **Communication challenges at end of life** created significant stress and anxiety, as patients' increasing difficulty in expressing needs, preferences, and wishes required staff to work harder to ensure these were accurately understood.<br>• **Engaging in advance care planning and end-of-life discussions** was particularly challenging when patients raised issues such as assisted suicide or euthanasia, leaving some professionals feeling unable to respond appropriately.<br>• **The intensity of end-of-life care**, especially when patients became fully dependent, sometimes affected professionals' capacity to meet the needs of other patients in inpatient settings.<br>• **Withdrawing supportive aids and devices** such as eye-gaze communication systems or non-invasive ventilation, was often experienced as removing a patient's final source of hope.<br>• **Inter-service communication difficulties** were common, particularly when specialist palliative care teams became involved late in the disease trajectory and lacked access to information about earlier discussions and care decisions.<br>• **Late involvement of services** and limited access to prior care plans meant that professionals frequently had to navigate gaps in knowledge about discussions that had previously taken place and interventions had already been offered, accepted, or declined.<br>• **Delays in access to essential aids and devices** resulted in professionals witnessing patients struggle without supports that could have improved quality of life if provided earlier.<br>• **A key benefit of working in specialist palliative care** was the presence of a strong team culture, with formal structures for debriefing and reflective practice that offered emotional and professional support—resources not consistently available in other services. |

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| **Multidisciplinary MND Outpatient Clinics** | • **Geographical variation in service provision** was a major source of frustration, with professionals in national and regional services highlighting disparities in what was available to patients depending on the region where they lived.<br>• **Reliance on community services** posed challenges, as levels of expertise in managing the complexity of MND varied. Professionals expressed concern about inequities in service delivery linked to vacant posts and differences in multidisciplinary team composition, which negatively affected continuity and quality of care available to plwMND.<br>• **Inadequate clinical environments** impacted on both the patient and clinician experience. Inappropriate toilet facilities, unsuitable seating and patient waiting areas, limited clinic space, and restricted clinic hours were some of the identified issues. These factors often left patients fatigued and distressed, while clinicians felt frustrated, guilty, and unable to fully address patient needs within time and environmental constraints.<br>• **Time pressures in clinic settings** made it difficult for professionals to address the full range of patients' physical, emotional, and psychosocial needs.<br>• **Supporting families and informal caregivers** was also challenging due to the lack of dedicated forums or appointments to identify and respond to their specific needs.<br>• **Despite these challenges, professionals in this area reported higher levels of job satisfaction** compared with those working in other services.<br>• **Feeling valued and appreciated** by patients and families was frequently described as rewarding, particularly in recognition of their knowledge and expertise in managing MND.<br>• **Working in this field offered personal perspective**, with many professionals reporting a deeper appreciation of their own health and life priorities.<br>• **Strong multidisciplinary team support** reduced feelings of isolation, with professionals describing confidence that challenges could be shared and addressed collaboratively. |

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| | • **The use of appropriate humour as a coping strategy** was more commonly reported among these professionals than among those in other services. |
| **Primary Care** | • **Professional isolation in community settings** was commonly reported, with clinicians describing uncertainty about the roles and involvement of other services, including specialist teams.<br>• **Accessing support from multidisciplinary colleagues** was often challenging, particularly when team members were geographically dispersed across different centres or locations.<br>• **Variation in experience and exposure to MND** contributed to uncertainty about providing accurate and up-to-date information, highlighting the need for ongoing guidance and communication from specialist teams across the disease trajectory, from diagnosis to end of life.<br>• **Continuity of care in community settings** was distinctive in MND, with individuals typically remaining under the care of the same primary care professionals throughout the course of illness, resulting in the formation of strong, long-term relationships with patients and their families. |
| **MND Charity Organisation** | • Nurses frequently assumed the role of care coordinator, and were responsible for communicating, educating, and supporting numerous professionals across a wide range of services. This was identified as a demanding aspect of the role, without streamlined or central documentation or communication systems.<br>• **Limitations in community resources** created significant challenges for professionals, who often witnessed patients and families struggle to manage care at home due to the lack of services tailored to the needs of individuals living with MND. These challenges included shortages of appropriate respite and long-term care facilities, as well as insufficient home care hours and a lack of carers able to meet complex care requirements.<br>• **Greater flexibility within the voluntary sector** enabled access to additional supports such as extra home care hours, counselling funding, and adaptive equipment, allowing professionals to deliver more responsive and effective care and reduce burden on families. |

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| | • **Service design tailored to working with an MND** population supported professional autonomy and time flexibility, with staff able to manage caseloads independently and benefiting from managerial understanding around workload pacing and visit duration.<br>• **Lone working in community settings** often meant nurses navigated sensitive end-of-life discussions without immediate MDT support. While colleagues working in other regions provided some support, this was not always as readily available as it would be in clinic or inpatient settings.<br>• **The care-coordinator role** nurses frequently assumed the role of care coordinator, and were responsible for communicating, educating, and supporting numerous professionals across a wide range of services. This was identified as a demanding aspect of the role, without streamlined or central documentation or communication systems. |
| **Residential Care** | • **Access to the multidisciplinary team m**ost of the care in this setting is provided by nursing and care assistants, often with limited access to other members of the MDT, despite the importance of multidisciplinary input in meeting the complex needs of individuals living with MND.<br>• **Managing highly complex care needs** was a central challenge, with staff often responsible for patients whose level of need could not be adequately met at home or in community settings.<br>• **Cognitive, behavioural, and communication difficulties** created particular challenges for care staff, especially in providing 24-hour support and accurately interpreting patients' needs and wishes, which could also impact care delivery for others within the setting.<br>• **The level of intensive care needs** meant that only a small number of individuals with MND could be cared for safely at any one time, due to the intensity and complexity of care required.<br>• **Family expectations and trust-building** were ongoing challenges, gaining the trust and meeting the expectations of family members who were often at a crisis point at the time of admission to residential care and had been providing a significant amount of intensive care |

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| | at home up until that point, made the transition of care difficult and meeting the families' expectations with the staffing and resources available could be difficult for the residential care team. |
| **Specialist Seating and Assistive Technology Services** | • **Delays in access to equipment and assistive technology** made it difficult to provide timely support, with devices often arriving too late or no longer being suitable for individuals' rapidly evolving needs.<br>• **Dependence on healthcare professionals from external services/family members** to help individuals integrate and use recommended technologies effectively, meant that the success of prescribed solutions was often outside of their control.<br>• **A strengths-based approach to care** was identified as a key benefit of working in this area, these professionals provided positive, hopeful interventions that focused on individuals' abilities, goals, and access to meaningful supports.<br>• **Organisational constraints on scheduling and outreach** limited flexibility, often restricting professionals' ability to respond promptly to patients' needs despite clinical urgency. |

# Impact of working with ALS/MND - Healthcare Professionals

Start of Block: Default Question Block

**Survey Title: The Impact of Working with Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND) on Healthcare Professionals.** **Information for Participants:** This study is being carried out by researchers in Trinity College Dublin, Ireland and intends to understand the potential impact of working with individuals living with ALS/MND on healthcare professionals' well-being and professional quality of life. We hope that this research will help to identify ways in which we can best support and sustain healthcare professionals to work with individuals and families living with ALS/MND. **Who is this survey for?** Healthcare professionals in Europe who are currently or were recently (within the past two years) employed in a service for individuals with ALS/MND. **Participating in the Survey:** If you currently work in an ALS/MND service, the survey will take approximately 20 minutes. If you are no longer working in an ALS/MND service, it will take approximately 10 minutes. We ask you to identify a time to complete the survey when you are least likely to be distracted by other demands. If you need to take a break, you can leave the survey and return within one week. Your responses will be saved during this time. Participation in this research is entirely voluntary. You will be asked to provide your consent to participate in the next section; once you start the survey, you can discontinue, by exiting the survey at any time. **The Survey:** There are **four parts** to this survey: **Part 1:** Demographic and work-related questions. **Part 2:** Questions about your understanding and experience of a phenomenon known as Moral Distress. **Part 3:** The Professional Quality of Life Scale (Stamm,2010). **Part 4:** The Brief Resilient Coping Scale (Sinclair & Wallston,2004). (*) There is an * beside some of the questions in the survey - this indicates that a response is required to the question before progressing to the next section. This is an anonymous survey, Qualtrics will not collect your IP address or any other information that could personally identify you. However, this also means that you will be unable to access your data, restrict processing, delete or receive your data in a portable format because we will be unable to identify which responses are yours. You have the right to discontinue the survey at any time by closing the Qualtrics tab of your internet browser. If you experience feelings of discomfort or upset, while answering any of the questions, we ask you to stop answering and to speak with a trusted colleague or medical professional about how you are feeling. **Ethics/Data Protection:** This study was approved by the School of Medicine, Research Ethics Committee in Trinity College Dublin, Ireland on the 22.10.24 (REF: 3500). If you have any concerns or questions, you can contact: The lead researcher Megan Walls – wallsme@tcd.ie. If you have any questions in relation to your rights under data protection law, you can contact the Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.dataprotection.ie

Page Break

**By clicking yes below you agree to the following;** I confirm that I have read and understood the participant information leaflet provided about this study. I understand that taking part in this study is entirely voluntary. I understand that I can leave this study at any time, by exiting the survey. I understand that I will not be paid for taking part in this study and participating may not directly benefit me. I understand that when I have completed the survey, my responses will not be distinguishable from others and cannot be removed. I will no longer be able to withdraw or access my study information, as there are no links between the responses and my identity. I know how to contact the research team if I need to. I consent to participating in this study:

- ○ Yes (1)
- ○ No (2)

*Skip To: QID66 If QID2 = No*

Page Break

I agree to my anonymous responses being used by the research team in Trinity College Dublin, Ireland for future research on professional well-being and ALS/MND care.

- ○ Yes (1)
- ○ No (2)

Page Break

**Part 1: Demographic and Work-Related Questions:** The first part of this survey asks demographic and work-related questions about your professional background and level of experience working with ALS/MND.

Page Break

Please select which of the following best describes you:

- ○ I currently work in a service for individuals with ALS/MND (1)
- ○ I don't currently work in a service for individuals with ALS/MND (2)

*Skip To: QID5 If QID3 = I don't currently work in a service for individuals with ALS/MND*

*Skip To: QID6 If QID3 = I currently work in a service for individuals with ALS/MND*

When was the last time you worked in a service for individuals with ALS/MND?

- Less than 6 months ago (1)
- 7 - 12 months ago (2)
- 13 - 18 months ago (3)
- 19 - 24 months ago (4)
- more than 24 months (5)

Page Break

Display this question:

*If QID3 = I currently work in a service for individuals with ALS/MND*

Do you work:

- Full time (1)
- Part time (2)

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

On average what percentage of your working week is working with individuals living with ALS/MND? (Move the slider to select the percentage)

0 10 20 30 40 50 60 70 80 90 100

% ()

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What is your professional role with individuals living with ALS/MND?

- ○ Medical (1)
- ○ Nursing (2)
- ○ Occupational Therapy (3)
- ○ Physiotherapy (4)
- ○ Speech and Language Therapy (5)
- ○ Dietitian (6)
- ○ Psychology (7)
- ○ Social Work (8)
- ○ Other (9) _____

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What gender do you identify as?

- ○ Male (1)
- ○ Female (2)
- ○ Non-binary/third gender (3)
- ○ Prefer not to say (4)

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

Which age category do you belong to?

- ○ Under 30 (1)
- ○ 31 - 50 (2)
- ○ 51+ (3)

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*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What country do you work in?

▼ Albania (1) ... Wales (110)

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*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

Country not listed, please specify:

_____

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*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

In what setting(s) do you work with individuals living with ALS/MND? Select all that apply:

- ☐ Inpatient facility (1)
- ☐ Outpatient service/clinic (2)
- ☐ Community – in individuals' homes (3)
- ☐ Other (please specify) (4) _____

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

How many years of experience do you have working with ALS/MND?

- ○ 0-5 (1)
- ○ 6-10 (2)
- ○ 11-20 (3)
- ○ 21+ (4)

Page Break

Display this question:

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

When you most recently worked with ALS/MND: Did you work:

- ○ Full time (1)
- ○ Part time (2)

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

On average what percentage of your working week was working with individuals living with ALS/MND? (Move the slider to select the percentage)

0 10 20 30 40 50 60 70 80 90 100

% ()

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

What was your professional role with individuals living with ALS/MND?

- Medical (1)
- Nursing (2)
- Occupational Therapy (3)
- Physiotherapy (4)
- Speech and Language Therapy (5)
- Dietitian (6)
- Psychology (7)
- Social Work (8)
- Other (9) _____

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

What gender do you identify as?

- ○ Male (1)
- ○ Female (2)
- ○ Non-binary/third gender (3)
- ○ Prefer not to say (4)

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

Which age category do you belong to?

- ○ Under 30 (1)
- ○ 31 - 50 (2)
- ○ 51+ (3)

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

In what country were you working with individuals living with ALS/MND?

▼ Albania (1) ... Wales (110)

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

Country not listed, please specify:

_____

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

In what setting(s) did you work with individuals living with ALS/MND? Select all that apply:

- ☐ Inpatient facility (1)
- ☐ Outpatient service/clinic (2)
- ☐ Community – in individuals' homes (3)
- ☐ Other (please specify) (4) _____

*Display this question:*

*If QID3 = I don't currently work in a service for individuals with ALS/MND*

How many years of experience do you have working with ALS/MND?

- ○ 0-5 (1)
- ○ 6-10 (2)
- ○ 11-20 (3)
- ○ 21+ (4)

Page Break

In the past two years, have you left a job as a healthcare professional **because of factors related to working with ALS/MND?**

- ○ No (1)
- ○ Yes (2)

*Skip To: QID17 If QID14 = No*

*Skip To: QID15 If QID14 = Yes*

Page Break

**Question:** In the past two years, have you left a job as a healthcare professional because of factors related to working with ALS/MND? **Answer:** Yes. What was the reason(s) for this?

_____

_____

_____

_____

_____

What did you do instead?

_____

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*Skip To: QID31 If Condition: What did you do instead? Is Displayed. Skip To: Part Two: Moral Distress Have you he....*

Page Break

Display this question:

*If QID3 = I currently work in a service for individuals with ALS/MND*

Are you **currently** considering leaving or changing your job because of factors related to working with ALS/MND?

- ○ No (1)
- ○ Yes (2)

*Skip To: QID20 If QID17 = No*

*Skip To: QID18 If QID17 = Yes*

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

**Question:** Are you currently considering leaving or changing your job because of factors related to working with ALS/MND? **Answer:** Yes What are the contributing factors?

_____

_____

_____

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What are you considering doing instead?

_____

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_____

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*Skip To: QID23 If Condition: What are you considering do... Is Displayed. Skip To: Have you ever taken time off work bec....*

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

Have you **ever** considered leaving or changing your job because of factors related to working with ALS/MND?

- ○ Yes (1)
- ○ No (2)

*Skip To: QID21 If QID20 = Yes*

*Skip To: QID23 If QID20 = No*

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

**Question:** Have you ever considered leaving or changing your job because of factors related to working with ALS/MND? **Answer:** Yes What was the contributing factor(s)?

_____

_____

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What did you consider doing instead?

_____

_____

_____

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

Have you **ever needed to take time off work** because of factors related to working with ALS/MND?

- ○ No (1)
- ○ Yes (2)

*Skip To: QID25 If QID23 = Yes*

*Skip To: Q13 If QID23 = No*

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

**Question:** Have you ever needed to take time off work because of factors related to working with ALS/MND? **Answer:** Yes How much time did you take off work?

_____

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

What was the reason(s) for needing to take time off work?

_____

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

Q13 Do you see yourself continuing to work with ALS/MND in the future?

- ○ Yes (1)
- ○ No (2)

*Display this question:*

*If Q13 = Yes*

**Question:** Do you see yourself continuing to work with ALS/MND in the future? **Answer:** Yes Why?

_____

_____

_____

*Display this question:*

*If Q13 = No*

**Question:** Do you see yourself continuing to work with ALS/MND in the future? **Answer:** No
Why not?

_____

_____

_____

Page Break

**Part 2: Moral Distress** Have you heard of the concept **Moral Distress** before?

- ○ No (1)
- ○ Yes (2)

Page Break

Moral distress can occur when healthcare professionals experience feelings of psychological unease, such as, **frustration, guilt, powerlessness, helplessness, stress, anxiety**, or **anger**, when they cannot carry out what they believe to be the ethical or appropriate action because of various barriers or constraints. Moral distress, in essence, may be seen as the inner conflict that can be experienced when healthcare professionals are torn between what they believe is the right thing to do for the people in their care and what they are able to do in their job or work environment.

Does this concept of moral distress resonate with your experience of working (or when you were working) with ALS/MND?

- ○ Yes (1)
- ○ No (2)
- ○ Not Sure (3)

Page Break

This section lists scenarios that have been recognised as occurring in clinical practice by professionals working with ALS/MND.

Please select 'yes' if you ever experience/experienced any of the following in your work with individuals living with ALS/MND; otherwise select 'no'.

| | Yes (1) | No (2) |
|---|---|---|
| Feel unable to effectively plan for the future care of individuals with ALS/MND because of my uncertainty regarding the trajectory of disease progression. (1) | ○ | ○ |
| Feel pressure to provide care/intervention that I don't believe will benefit the individual with ALS/MND at the request of others, such as family, senior colleagues, or other services. (2) | ○ | ○ |
| Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. (3) | ○ | ○ |
| Feel that by initiating future care planning, I am adding to the individuals psychological distress. (4) | ○ | ○ |
| Feel unable to offer individuals with ALS/MND and their families the emotional support or comfort they need. (5) | ○ | ○ |
| Have difficulty communicating hope or optimism for individuals with ALS/MND with no available cure for the disease. (6) | ○ | ○ |
| Worry that the wishes of individuals with ALS/MND are not being respected when problems with their communication arise. (8) | ○ | ○ |
| Feel unable to provide an intervention that could benefit the individual with ALS/MND because of cognitive or behavioral changes. (9) | ○ | ○ |
| Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. (10) | ○ | ○ |
| Witness individuals with ALS/MND in distress or pain due to poorly managed symptoms. (11) | ○ | ○ |

| | | |
|---|---|---|
| Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. (12) | ○ | ○ |
| Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. (13) | ○ | ○ |
| Feel unable to effectively deliver care for an individual with ALS/MND due to a breakdown in the patient-clinician relationship. (25) | ○ | ○ |
| Struggle to meet the needs of both individuals with ALS/MND and their family members because of their conflicting priorities or opinions. (14) | ○ | ○ |
| Have difficulty implementing care or interventions without family or informal caregiver support. (15) | ○ | ○ |
| Witness compromised care for individuals with ALS/MND because of poor communication between healthcare professionals. (16) | ○ | ○ |
| Witness care for individuals with ALS/MND being negatively affected because of staffing vacancies within a team or service. (17) | ○ | ○ |
| Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the persons care. (18) | ○ | ○ |
| Struggle to meet the needs/expectations of individuals with ALS/MND or their families due to limitations imposed by my organisation's policies or procedures. (19) | ○ | ○ |
| Witness individuals with ALS/MND struggling while waiting for necessary aids, devices, or services. (20) | ○ | ○ |

| | | |
|---|---|---|
| Experience individuals with ALS/MND receiving unequal access to services/resources depending on the region where they live. (21) | ○ | ○ |
| Witness compromised care for individuals with ALS/MND due to lack of equipment/resources/bed capacity. (22) | ○ | ○ |
| Feel restricted to prioritise only certain aspects of care for individuals with ALS/MND due to limited time during appointments. (23) | ○ | ○ |
| Be required to care for more individuals with ALS/MND than I can safely care for. (24) | ○ | ○ |
| | Yes (1) | No (2) |
| Feel unable to effectively plan for the future care of individuals with ALS/MND because of my uncertainty regarding the trajectory of disease progression. (1) | ○ | ○ |
| Feel pressure to provide care/intervention that I don't believe will benefit the individual with ALS/MND at the request of others, such as family, senior colleagues, or other services. (2) | ○ | ○ |
| Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. (3) | ○ | ○ |
| Feel that by initiating future care planning, I am adding to the individuals psychological distress. (4) | ○ | ○ |
| Feel unable to offer individuals with ALS/MND and their families the emotional support or comfort they need. (5) | ○ | ○ |
| Have difficulty communicating hope or optimism for individuals with ALS/MND with no available cure for the disease. (6) | ○ | ○ |

| | | |
|---|---|---|
| Worry that the wishes of individuals with ALS/MND are not being respected when problems with their communication arise. (8) | ○ | ○ |
| Feel unable to provide an intervention that could benefit the individual with ALS/MND because of cognitive or behavioral changes. (9) | ○ | ○ |
| Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. (10) | ○ | ○ |
| Witness individuals with ALS/MND in distress or pain due to poorly managed symptoms. (11) | ○ | ○ |
| Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. (12) | ○ | ○ |
| Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. (13) | ○ | ○ |
| Feel unable to effectively deliver care for an individual with ALS/MND due to a breakdown in the patient-clinician relationship. (25) | ○ | ○ |
| Struggle to meet the needs of both individuals with ALS/MND and their family members because of their conflicting priorities or opinions. (14) | ○ | ○ |
| Have difficulty implementing care or interventions without family or informal caregiver support. (15) | ○ | ○ |
| Witness compromised care for individuals with ALS/MND because of poor communication between healthcare professionals. (16) | ○ | ○ |

| | | |
|---|---|---|
| Witness care for individuals with ALS/MND being negatively affected because of staffing vacancies within a team or service. (17) | ○ | ○ |
| Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the persons care. (18) | ○ | ○ |
| Struggle to meet the needs/expectations of individuals with ALS/MND or their families due to limitations imposed by my organisation's policies or procedures. (19) | ○ | ○ |
| Witness individuals with ALS/MND struggling while waiting for necessary aids, devices, or services. (20) | ○ | ○ |
| Experience individuals with ALS/MND receiving unequal access to services/resources depending on the region where they live. (21) | ○ | ○ |
| Witness compromised care for individuals with ALS/MND due to lack of equipment/resources/bed capacity. (22) | ○ | ○ |
| Feel restricted to prioritise only certain aspects of care for individuals with ALS/MND due to limited time during appointments. (23) | ○ | ○ |
| Be required to care for more individuals with ALS/MND than I can safely care for. (24) | ○ | ○ |

Please describe any other clinical situation(s) where you felt unable to provide the care you wanted to for someone with ALS/MND.

_____

*Carry Forward Selected Choices from ""*

The statements you selected 'yes' to experiencing in the previous section are now listed here. **Please select 5** of these clinical scenarios (in any order) that you do or would find most stressful when working with individuals living with ALS/MND.

- [ ] Feel unable to effectively plan for the future care of individuals with ALS/MND because of my uncertainty regarding the trajectory of disease progression. (1)

- [ ] Feel pressure to provide care/intervention that I don't believe will benefit the individual with ALS/MND at the request of others, such as family, senior colleagues, or other services. (2)

- [ ] Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. (3)

- [ ] Feel that by initiating future care planning, I am adding to the individuals psychological distress. (4)

- [ ] Feel unable to offer individuals with ALS/MND and their families the emotional support or comfort they need. (5)

- [ ] Have difficulty communicating hope or optimism for individuals with ALS/MND with no available cure for the disease. (6)

- [ ] Worry that the wishes of individuals with ALS/MND are not being respected when problems with their communication arise. (7)

- [ ] Feel unable to provide an intervention that could benefit the individual with ALS/MND because of cognitive or behavioral changes. (8)

- [ ] Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. (9)

- [ ] Witness individuals with ALS/MND in distress or pain due to poorly managed symptoms. (10)

- [ ] Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. (11)

☐ Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. (12)

☐ Feel unable to effectively deliver care for an individual with ALS/MND due to a breakdown in the patient-clinician relationship. (13)

☐ Struggle to meet the needs of both individuals with ALS/MND and their family members because of their conflicting priorities or opinions. (14)

☐ Have difficulty implementing care or interventions without family or informal caregiver support. (15)

☐ Witness compromised care for individuals with ALS/MND because of poor communication between healthcare professionals. (16)

☐ Witness care for individuals with ALS/MND being negatively affected because of staffing vacancies within a team or service. (17)

☐ Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the persons care. (18)

☐ Struggle to meet the needs/expectations of individuals with ALS/MND or their families due to limitations imposed by my organisation's policies or procedures. (19)

☐ Witness individuals with ALS/MND struggling while waiting for necessary aids, devices, or services. (20)

☐ Experience individuals with ALS/MND receiving unequal access to services/resources depending on the region where they live. (21)

☐ Witness compromised care for individuals with ALS/MND due to lack of equipment/resources/bed capacity. (22)

☐ Feel restricted to prioritise only certain aspects of care for individuals with ALS/MND due to limited time during appointments. (23)

☐ Be required to care for more individuals with ALS/MND than I can safely care for. (24)

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

**Moral Distress Thermometer** As defined by Wocial (2013): Moral distress occurs when you believe you know the ethically correct thing to do, but **something or someone restricts your ability to pursue the correct course of action**. Please select the number (0-10) on the Moral Distress Thermometer Scale that best describes how much moral distress you have been experiencing related to work in the past week including today.

- 10 Worst Possible (1)
- 9 (2)
- 8 Intense (3)
- 7 (4)
- 6 Distressing (5)
- 5 (6)
- 4 Uncomfortable (7)
- 3 (8)
- 2 Mild (9)
- 1 (10)
- 0 None (11)

Page Break

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

**Part 3: Professional Quality of Life**

*Display this question:*

*If QID3 = I currently work in a service for individuals with ALS/MND*

When you help people you have direct contact with their lives. As you may have found, your compassion for those you help can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a healthcare professional (Stamm, 2010). Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you

experienced these things in the last 30 days. **In this section 'people I help' relates specifically to your work In with individuals living with ALS/MND**. .

| | 1 Never (1) | 2 Rarely (2) | 3 Sometimes (3) | 4 Often (4) | 5 Very Often (5) |
|---|---|---|---|---|---|
| I am happy. (1) | ○ | ○ | ○ | ○ | ○ |
| I am preoccupied with more than one person I help. (2) | ○ | ○ | ○ | ○ | ○ |
| I get satisfaction from being able to help people. (3) | ○ | ○ | ○ | ○ | ○ |
| I feel connected to others. (4) | ○ | ○ | ○ | ○ | ○ |
| I jump or am startled by unexpected sounds. (5) | ○ | ○ | ○ | ○ | ○ |
| I feel invigorated after working with those I help. (6) | ○ | ○ | ○ | ○ | ○ |
| I find it difficult to separate my personal life from my life as a healthcare worker. (7) | ○ | ○ | ○ | ○ | ○ |
| I am not as productive at work because I am losing sleep over traumatic experiences of a person I help. (8) | ○ | ○ | ○ | ○ | ○ |
| I think that I might have been affected by the traumatic stress of those I help. (9) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I feel trapped by my job as a healthcare worker. (10) | ○ | ○ | ○ | ○ | ○ |
| Because of my work, I have felt "on edge" about various things. (11) | ○ | ○ | ○ | ○ | ○ |
| I like my work as a healthcare worker. (12) | ○ | ○ | ○ | ○ | ○ |
| I feel depressed because of the traumatic experiences of the people I help. (13) | ○ | ○ | ○ | ○ | ○ |
| I feel as though I am experiencing the trauma of someone I have helped. (14) | ○ | ○ | ○ | ○ | ○ |
| I have beliefs that sustain me. (15) | ○ | ○ | ○ | ○ | ○ |
| I am pleased with how I am able to keep up with work techniques and protocols. (16) | ○ | ○ | ○ | ○ | ○ |
| I am the person I always wanted to be. (17) | ○ | ○ | ○ | ○ | ○ |
| My work makes me feel satisfied. (18) | ○ | ○ | ○ | ○ | ○ |
| I feel worn out because of my work as a healthcare worker. (19) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I have happy thoughts and feelings about those I help and how I could help them. (20) | ○ | ○ | ○ | ○ | ○ |
| I feel overwhelmed because my case workload seems endless (21) | ○ | ○ | ○ | ○ | ○ |
| I believe I can make a difference through my work. (22) | ○ | ○ | ○ | ○ | ○ |
| I avoid certain activities or situations because they remind me of frightening experiences of the people I help. (23) | ○ | ○ | ○ | ○ | ○ |
| I am proud of what I can do to help. (24) | ○ | ○ | ○ | ○ | ○ |
| As a result of my work, I have intrusive, frightening thoughts. (25) | ○ | ○ | ○ | ○ | ○ |
| I feel "bogged down" by the system. (26) | ○ | ○ | ○ | ○ | ○ |
| I have thoughts that I am a "success" as a healthcare worker. (27) | ○ | ○ | ○ | ○ | ○ |
| I can't recall important parts of my work with individuals with ALS/MND. (28) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I am a very caring person. (29) | ○ | ○ | ○ | ○ | ○ |
| I am happy that I chose to do this work. (30) | ○ | ○ | ○ | ○ | ○ |
| | 1 Never (1) | 2 Rarely (2) | 3 Sometimes (3) | 4 Often (4) | 5 Very Often (5) |
| I am happy. (1) | ○ | ○ | ○ | ○ | ○ |
| I am preoccupied with more than one person I help. (2) | ○ | ○ | ○ | ○ | ○ |
| I get satisfaction from being able to help people. (3) | ○ | ○ | ○ | ○ | ○ |
| I feel connected to others. (4) | ○ | ○ | ○ | ○ | ○ |
| I jump or am startled by unexpected sounds. (5) | ○ | ○ | ○ | ○ | ○ |
| I feel invigorated after working with those I help. (6) | ○ | ○ | ○ | ○ | ○ |
| I find it difficult to separate my personal life from my life as a healthcare worker. (7) | ○ | ○ | ○ | ○ | ○ |
| I am not as productive at work because I am losing sleep over traumatic experiences of a person I help. (8) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I think that I might have been affected by the traumatic stress of those I help. (9) | ○ | ○ | ○ | ○ | ○ |
| I feel trapped by my job as a healthcare worker. (10) | ○ | ○ | ○ | ○ | ○ |
| Because of my work, I have felt "on edge" about various things. (11) | ○ | ○ | ○ | ○ | ○ |
| I like my work as a healthcare worker. (12) | ○ | ○ | ○ | ○ | ○ |
| I feel depressed because of the traumatic experiences of the people I help. (13) | ○ | ○ | ○ | ○ | ○ |
| I feel as though I am experiencing the trauma of someone I have helped. (14) | ○ | ○ | ○ | ○ | ○ |
| I have beliefs that sustain me. (15) | ○ | ○ | ○ | ○ | ○ |
| I am pleased with how I am able to keep up with work techniques and protocols. (16) | ○ | ○ | ○ | ○ | ○ |
| I am the person I always wanted to be. (17) | ○ | ○ | ○ | ○ | ○ |
| My work makes me feel satisfied. (18) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I feel worn out because of my work as a healthcare worker. (19) | ○ | ○ | ○ | ○ | ○ |
| I have happy thoughts and feelings about those I help and how I could help them. (20) | ○ | ○ | ○ | ○ | ○ |
| I feel overwhelmed because my case workload seems endless (21) | ○ | ○ | ○ | ○ | ○ |
| I believe I can make a difference through my work. (22) | ○ | ○ | ○ | ○ | ○ |
| I avoid certain activities or situations because they remind me of frightening experiences of the people I help. (23) | ○ | ○ | ○ | ○ | ○ |
| I am proud of what I can do to help. (24) | ○ | ○ | ○ | ○ | ○ |
| As a result of my work, I have intrusive, frightening thoughts. (25) | ○ | ○ | ○ | ○ | ○ |
| I feel "bogged down" by the system. (26) | ○ | ○ | ○ | ○ | ○ |
| I have thoughts that I am a "success" as a healthcare worker. (27) | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|---|---|---|---|---|
| I can't recall important parts of my work with individuals with ALS/MND. (28) | ○ | ○ | ○ | ○ | ○ |
| I am a very caring person. (29) | ○ | ○ | ○ | ○ | ○ |
| I am happy that I chose to do this work. (30) | ○ | ○ | ○ | ○ | ○ |

Page Break

**Part 4: Brief Resilient Coping Scale** These questions ask about how you typically respond to difficult circumstances or stressors (Sinclair & Wallston, 2004).

Consider how well the following statements describe your behavior and actions.

| | (1) Does not describe me at all (1) | (2) Does not describe me (2) | (3) Neutral (3) | (4) Describes me (4) | (5) Describes me very well (5) |
|---|---|---|---|---|---|
| I look for creative ways to alter difficult situations. (1) | ○ | ○ | ○ | ○ | ○ |
| Regardless of what happens to me, I believe I can control my reaction to it. (2) | ○ | ○ | ○ | ○ | ○ |
| I believe I can grow in positive ways by dealing with difficult situations. (3) | ○ | ○ | ○ | ○ | ○ |
| I actively look for ways to replace the losses I encounter in life. (4) | ○ | ○ | ○ | ○ | ○ |

Is there anything that you find (or previously found) helpful/supportive for you as a healthcare professional when working with ALS/MND?

_____

_____

_____

_____

_____

*Display this question:*

*If QID2 = No*

Thank you for considering to participate in this survey. If you change your mind please email the lead researcher Megan Walls (wallsme@tcd.ie) for access to a new link that will allow you to complete the survey. Thanks for your time!

**End of Block: Default Question Block**

## **Appendix M:** Tools Identified and Considered to Measure Moral Distress

| ***Outcome: MORAL DISTRESS*** | ***Initial Considerations*** | ***Acceptability and Utility*** | ***Measurement Properties*** | ***Selected/ Not Selected*** *Why?* |
|---|---|---|---|---|
| ***Corley's Moral Distress Scale***<br><br>*(Corley* et al*., 2001)*<br>↓<br>*(Corley et al., 2005)*<br>↓<br>*(Hamric and Blackhall, 2007)* | The first measure of moral distress: **The Moral Distress Scale**, was developed by Corley et al., (2001), based on qualitative data and an extensive literature review.<br><br>The framework guiding the development of the moral distress scale (MDS) included Jameton's original conceptualisation of moral distress, House and Rizzo's role conflict theory, and Rokeach's value theory.<br><br>Six new items were added to the original 32 items by Corley, et al. in 2005. This scale was developed for and tested on intensive care nurses.<br><br>In 2007 Hamric et al. reduced the number of items from 38 to 19 and tested them on Intensive | **Administration:**<br>0-6 Likert scale measuring frequency and intensity of moral distress.<br><br>Higher scores reflect higher levels of moral distress.<br><br>Subjects are instructed to leave an item blank if they have no experience of the moral problem. | The most widely used measure of moral distress in nurses. Initially validated with US nurses: The first testing of the MDS yielded evidence of validity and reliability.<br><br>**Reliability:**<br>**Test re-test reliability** with a convenience sample of staff nurses ($n$ = 35) was Cronbach's α = 0.86 ($p$ < 0.01).<br><br>All factors had acceptable levels of **internal consistency.**<br>The three factors identified were:<br>Factor 1 ± individual responsibility: 20 items (Cronbach's α = 0.97),<br>Factor 2 ± not in patient's best interest: 7 items (Cronbach's α = 0.82), | Not Selected<br>• Tested only for use with nurses. Not relevant to wider HCP population.<br>• Outdated version - more recent versions of the scale available.<br>• Items not specifically relevant for those working with MND population.<br>• Focuses on moral dilemmas related to patient care, team and system root causes not included. |

| | | | | |
|---|---|---|---|---|
| | Care Units (ICUs), physicians and registered nurses engaged in direct patient care.<br>This adaptation narrowly focused on end-of-life care in ICU settings and generally lacked utility for non-ICU settings.<br><br>Hamric identified the absence of a tool measuring Moral Distress across disciplines and settings. | | Factor 3 ± deception: 3 items (Cronbach's α = 0.84). | |
| ***Moral Distress Scale-Revised***<br>*(Hamric, Borchers and Epstein, 2012)* | In 2012 Hamrick et al., revised the Moral Distress Scale to make it applicable to all healthcare professionals and acute care clinical settings. The lead author consulted with Corley, who supported a major revision of her existing scale.<br><br>It was designed to accomplish three objectives: (1) include more root causes of moral distress; (2) expand its use in non-ICU settings; and (3) make it appropriate for use | **Administration:**<br>21 items<br>Has been extensively validated internationally including in Turkey, Italy, Australia, China, Korea, Brazil, Sweden, and Iran.<br><br>**Scoring:**<br>Corley's original Likert 1–7 scale was replaced with a 0–4 scale.<br><br>Each of the 21 items are scored by participants in terms of how often the situation arises (frequency) and how distressing the situation | Has been used in numerous studies with good reliability and validity.<br><br>Initially psychometrically tested in a group of registered nurses and physicians in eight ICUs in the US.<br><br>**Reliability:** Reliability of the instrument was tested by calculating the Cronbach's alpha for nurse (0.89) and physician populations (0.67 overall, 0.69 for attending physicians, 0.75 for | Not Selected<br>• Outdated version, there is a more recent version of the scale available.<br>• Focuses mostly on clinical and patient root causes, little emphasis on team and system causes of Moral Distress frequently reported by HCPs working with MND.<br>• Time consuming to complete as all items need to be rated twice for |

by multiple healthcare disciplines.

It is designed to be used by both healthcare organisations and researchers.

To increase the applicability of the MDS-R to populations beyond nursing, six parallel versions of the scale were developed. Three focus on providers who practice in adult settings: nurses, physicians, and other health care professionals; the remaining three versions focus on these same provider groups in pediatric settings.

The scoring scheme was also revised. Corley's original Likert 1–7 scale was replaced with a 0–4 scale.

Open-text questions were also included to allow participants to add items they believe are morally distressing, this encourages is when it arises (intensity).

The scale for frequency ranges from 0 (never) to 4 (very frequently), and for intensity from 0 (none) to 4 (great extent).

Items that have never been experienced or are not seen as distressing do not contribute to an individual's level of moral distress or to their MDS-R score.

While the frequency and intensity scores for each item can be summed and examined separately, it is also possible to compute a composite score useful for multivariate analyses.

This composite score for overall moral distress is computed in a two-part procedure.

First the frequency score and the intensity score for pediatric physicians) as well as for all participants combined (0.88).

**Content Validity:** Four content experts on moral distress and a doctoral prepared colleague who directs a multihospital nursing ethics program—tested the content validity of the MDS-R. An 88% interrater agreement was achieved on primary and secondary root causes; full agreement was reached for 19 of 21 items. As a result, one item was substantially reworded, one was eliminated. A nurse and physician who led a palliative care service at a large, multihospital system reviewed the final items for the appropriateness and clarity of content, and supported all revisions.

**Construct Validity:** Construct validity was evaluated through hypothesis testing. Each

frequency and intensity.

- There is no timepoint provided therefore could be assessing an accumulation of prior experiences of MD that have resolved rather than current experiences.

the identification of new domains and furthers the state of the science in this field.

Some authors have adapted this instrument to other clinical settings such as residential and community care environments (Burston et al., 2017), psychiatric service (Ohnishi et al., 2010), nursing in hemato-oncology services (Fruet et al., 2017) and, primary health care (Barth et al., 2018).

Other authors have translated and validated this instrument in different languages and many authors tested the instrument on other healthcare workers, such as occupational therapists (Penny et al., 2016), physicians (Abbasi et al., 2014), social workers (Lev and Ayalon, 2018), nursing technicians and assistants (Dalmolin et al., 2014a), stepdown unit providers (physicians,

each of the 21 items are multiplied. This creates a new variable for each item, the frequency × intensity (fxi) score, which ranges from 0 to 16.

Items rarely experienced or minimally distressing have low fxi scores, and items experienced frequently and as most distressing have higher fxi scores.

Next, the composite score is obtained by summing each item's fxi score. Using this scoring scheme allows all items marked as never experienced or not distressing to be eliminated from the composite score, giving a more accurate reflection of actual moral distress. The resulting score based on 21 items has a range of 0–336.

of the four hypotheses were supported, although the first hypothesis was supported only for the nurse group.
Nurses with more experience in their current positions did demonstrate higher moral distress.
Higher levels of moral distress in clinicians with greater years' experience (moral residue)
Higher levels of moral distress in nurses than in physicians
Lower levels of MD in healthcare settings with positive/ good ethical climates
Higher levels of MD in clinicians considering leaving their position.

The findings from this study support the important relationships between provider moral distress, the ethical climate of healthcare settings, and the retention of experienced healthcare professionals.

| | | | | |
|---|---|---|---|---|
| | nurses, nurse technicians and respiratory therapists) (Fumis et al., 2017).<br><br>It has therefore been widely used and validated for healthcare providers from a range of different clinical backgrounds and contexts. | | | |
| ***Measure of Moral Distress for Health Care Professionals*** *(Epstein* et al.*, 2019)* | The MMD-HP is a substantial revision of the Moral Distress Scale-Revised (MDS-R).<br><br>It aims to capture team and system-level sources of moral distress, reduce repetition of similar root causes, and simplify its use more fully.<br><br>The instrument's 27 items represent the most currently understood causes of moral distress.<br><br>It is usable by all healthcare practitioners in both adult and pediatric, critical, long-term, or acute care settings. | **Administration:**<br>27 items<br>Can be distributed electronically and has been distributed by the authors online via Qualtrics.<br>Available free of charge.<br>No training requirements.<br><br>**Scoring:**<br>The same scoring system is used as the MDS-R, described above.<br><br>Participants rate each item on a Likert scale for how often it occurs in their practice (frequency: 0 = never, 4 = very frequently) and for how distressing it is when it occurs (distress: 0 = | Psychometrically tested with nurses, physicians, and other health care clinicians at two academic medical centers.<br><br>**Face Validity:** Evaluated by a group of experts and clinicians. Face validity testing revealed that the new instrument was easily completed by individuals of different professions and in different clinical areas.<br><br>Cronbach's alpha computations suggested good reliability for the overall sample (α = 0.93) and for each provider group; nurse α = 0.931, | Not Selected<br>• This tool was strongly considered due to its applicability for use with a wide range of HCPs and across a wide range of clinical settings.<br>• The inclusion of a number of system and unit root causes also made this tool more applicable for the current study population than any previous tool.<br>• Many of the items were however felt not to fully apply or did not accurately |

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| This updated version of the tool includes two new items related to system-level problems that apply more broadly to all HCP's, not only those at the bedside. It therefore assesses, three root causes of moral distress at patient, team and system levels.<br><br>The tool also captures more system-level root causes than previous tools and is intended to capture the key root causes affecting other HCP's, not just nurses and physicians as traditionally studied to provide a greater understanding of the wider HCP experience.<br><br>The MMD-HP allows for assessment of specific root causes that can then be used as a diagnostic tool to target interventions for particular units, teams, and professionals. | none, 4 = very distressing).<br><br>**Interpretation:** Since this is a relatively new instrument, it is difficult to say what scores constitute high versus low moral distress.<br><br>One approach to interpretation of scores involves creating "cut scores."<br>Hamric and Blackhall (2007) divided the sample scores into three categories or "cut scores" (high, medium, and low groups; 1/3 of the sample in each category) and then compared the high and low scorers against selected other variables.<br><br>A second approach is to calculate means and standard deviations for those intending to leave their position now due to moral distress and for those not intending to leave their position now | physician α = 0.901, other α = 0.936.<br><br>Item-to-item correlations and changes in alpha calculations if particular items were deleted were evaluated and no problematic items were identified.<br><br>Construct Validity:<br>Hypothesis testing:<br>1. MMD-HP scores were significantly higher for nurses than for physicians<br>2. MMD-HP scores were significantly higher for participants currently considering leaving their position due to moral distress than for those not considering leaving.<br>3. Higher MMD-HP scores were associated with | capture many of the likely causes of MD identified by professionals working with MND in the qualitative phases of this current research.<br>• The questions developed to measure the root causes of MD for professionals working specifically with MND in this study were largely guided by the MMD-HP tool, and the factor classification of patient, team and system level causes.<br>• Participants intention to leave or change career will also be considered in conjunction with their MD score and frequency analysis undertaken to determine the |

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| | due to moral distress. Those intending to leave should have higher levels of moral distress than those not intending to leave.<br><br>In this 2019 validation study, respondents thinking of leaving their positions due to moral distress had an MMD-HP mean score of 168.4; those not thinking of leaving their positions had an MMD-HP mean score of 94.3. A caveat with this approach is that the two groups are likely to be unequal which may impact statistical analysis.<br>The number of participants not considering leaving their position due to moral distress is generally much larger than the number of participants considering leaving. Therefore, it is important to clearly describe your rationale for whichever | poorer perceptions of workplace ethical climate.<br>4. Demonstrated a factor structure that conforms to the three-level root causes of moral distress, including the understanding that some root causes operate at more than one level.<br><br>Validity testing indicates that the MMD-HP performs similarly to the previous measure of moral distress from which it was derived.<br><br>In addition, the new instrument shows a factor structure that conforms to the three-level root causes seen in moral distress, including the understanding that some root causes operate at more than one level. | highest root causes of MD for the overall sample and sub-groups of the sample. |

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| | | method you use in your report.<br><br>It is also important to consider that Likert scales such as these with a mid-point can introduce a central tendency bias as participants may avoid extreme response categories. | These findings indicated that patient-level root causes, especially those related to overly aggressive treatment at the end of life, continue to be the most morally distressing for all HCPs, especially nurses and other direct patient providers.<br><br>Three of the top-ranked root causes, excessive documentation, lack of resources, and lack of administrative action, are newly added to the MMD-HP.<br><br>Differences in root causes were seen among groups, providing promising **discriminant validity** of the MMD-HP. | |
| ***Moral Distress Risk Scale (MDRS)***<br><br>*(Schaefer, Zoboli and Vieira, 2019)* | The Moral Distress Risk Scale (MDRS) was conceived to assess the exposition to risk factors of moral distress. It was designed to be used across a range of clinical settings. | **Administration:**<br>The instrument is made up 7 factors and 30 items.<br>• Organisational and Management issues<br>• End of life care | Originally, psychometrically tested in a sample of Brazilian nurses, based in hospitals and primary care. | Not Selected<br>• Designed primarily for use with nurses.<br>• Not congruent with the aims of this current study, to |

To overcome the subjective nature of Moral Distress, this tool aimed to look at this phenomenon through the view of the risk factors, instead of the causes, shifting the focus from merely assessing the occurrence of moral distress to identifying **risk factors** that predispose healthcare workers to such experiences.

The MDRS supports efforts to mitigate moral distress by improving work conditions, leadership, communication, and resource allocation.

Developed for nurses working in a range of healthcare contexts.

- Autonomy
- Workload
- Security
- Resources
- Conflict

For each factor, the participants express the frequency of the exposition to these factors ranging from 1 (never) to 4 (always).

In line with other tools there is a sub section at the end that asked participants if they felt that the risk factors presented could be considered as risk factors for moral distress, if they were currently experiencing moral distress and if they would leave their current position because of moral distress if they could.

**Scoring:**
Schaefer et al considered mean scores between 1 and 2 to be associated

The psychometric evaluation evidence had acceptable results, with an adequate factorial analysis, a high internal consistency, and a reasonable percentage of variance explained.

identify current causes of moral distress relevant to working with MND and not risk factors.

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| | | with a low risk for moral distress, a score between 2 and 3 with a moderate risk for moral distress, and a score between 3 and 4 with a higher risk for moral distress. | | |
| ***Moral Distress Questionnaire (MDQ)***<br><br>*(Eizenberg, Desivilya and Hirschfeld, 2009)* | The aim was to develop a culturally sensitive moral distress questionnaire (MDQ) among nurses employed in a variety of work settings.<br><br>30 nurses participated in five focus groups to inform tool development; this then formed the basis for adapting existing structured measures of moral distress.<br><br>The findings indicated that experiences of moral distress were primarily construed as a result of external or institutional constraints, such as insufficient resources (e.g. medications not covered by the national health insurance), understaffing and hence job overload and insufficient or inappropriate | **Administration:**<br>15 item questionnaire – 10 minutes to administer.<br><br>The questionnaire items describe specific situations with which nurses face during everyday care of patients and their families, for example 'I was forced to provide incomplete care to the patient, owing to work overload'.<br>Respondents are asked to rate on a 6-point Likert type scale (1 = not at all and up to 6 = very large extent) the extent to which the described situation caused them to experience moral distress. | Psychometrically tested among nurses in a variety of work settings (hospitals, the community, nursing homes, chronic care facilities, and mental hospitals).<br><br>Has not been widely used in other research.<br><br>To examine the variation of responses, they were listed in a frequency table for each of the items. The distribution indicated sufficient variance in responses, with a slight tendency toward an asymmetrical positive skewing. No clear floor or ceiling effects were found. | Not Selected<br>• Not suitable for wider HCP population, developed specifically and only tested for use with nurses.<br>• Statements not relevant to the work of those working with MND. |

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| space to give high quality care.<br><br>Another major source of distress associated with ethical issues – internal conflict or pressure – Internal conflict included mainly issues associated with relationships among nurses, with their supervisors and with physicians.<br><br>Most respondents viewed the conflicting professional approaches of nurses and physicians as precursors of moral distress, with nurses emphasising patient dignity and psychological well-being and physicians primarily focusing on patients' survival. | | **Factor Analysis** identified three factors representing moral distress: (1) problems caused by work relationships among staff; (2) problems due to lack of resources; and (3) problems caused by time pressure.<br><br>**Construct validity:**<br>To provide evidence for the construct validity of the questionnaire, a comparison was made between two groups; hospital nurses and community clinic nurses, as it was assumed that differences would be observed in pressure resulting from different moral dilemmas. To examine these differences, t-tests for independent samples were conducted. A statistically significant difference was found between means for two of the three factors (relationships and time). |

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| | | | These differences provide evidence for the **discriminant validity** of the questionnaire.<br><br>**Test- retest reliability:** The questionnaire was administered at two points 1 month apart. The correlation between the two measurements was 0.624 (P < 0.001). | |
| ***Moral Distress Thermometer***<br><br>*(Wocial and Weaver, 2013)* | Developed as a tool to measure 'real-time' moral distress.<br><br>Also developed as a tool to measure the impact of interventions designed to reduce MD in clinical settings.<br><br>It was developed based on the nursing literature, but considering its simplicity and brevity can be easily used across a range of clinical settings.<br><br>The major advantage of the MDT is its simplicity, brevity, and quick time to complete. | It is a single-item visual analogue scale with an 11- point verbal numerical rating scale of 0 to 10, with 0 representing the absence of moral distress and 10 representing the worst possible moral distress.<br><br>Participants are given the definition; '*Moral distress occurs when you believe you know the ethically correct thing to do, but something or someone restricts your ability to pursue the right course of actio*n', | Psychometrically tested in a sample of acute care nurses in the US.<br><br>Limited psychometric testing in a small homogeneous sample.<br><br>**Reliability:** Internal consistency estimates for adult (coefficient alpha = 0.904) and pediatric (coefficient alpha = 0.928) MDS 2009 scales was acceptable.<br><br>**Convergent Validity:** though evaluation of the MDT provided evidence for convergent validity with the MDS 2009, a | Selected<br>• Ability to measure 'real-time' moral distress and will therefore give a good understanding of the current magnitude of the problem.<br>• Ability to provide a numerical representation of current level of moral distress experienced as an add on to understanding the primary root causes for those working with MND |

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| | A major limitation is the sporadic use of descriptors for only some numbers on the scale, which may result in a selection bias of those numbers. | Respondents are asked to reflect on their clinical practice in the last 2 weeks and identify on the thermometer the level of Moral Distress they are currently experiencing.<br><br>Every second or even number on the scale has a descriptor word.<br><br>0-None<br>2 – Mild<br>4- Uncomfortable<br>6- Distressing<br>8- Intense<br>10- Worst Possible<br><br>There are no descriptors provided for the odd numbers 1,3,5,7,9. | significant limitation of this work is the absence of separate reliability testing of the MDT.<br><br>Contrasts indicated that nurses who had never considered leaving their position had lower mean MDT than either those who had considered leaving ($P < 0.001$) or those who had left ($P = 0.004$).<br><br>As a result of the statistical relationship between the MDT score and nurses' self-report of 'consider leaving a position', the MDT has potential as a screening tool to identify nurses who may be at risk for leaving a position as a consequence of their level of MD. | in the previous section of the survey.<br>• Has previously been used as an add on to the MMD-HP for this purpose.<br>• Brevity, simplicity and rapid administration time. |
| *Additional Measures:* | MDS for psychiatric nurses (MDS-P)<br>Moral Distress in Dementia Care Survey (MDDCS)<br>Moral distress questionnaire for clinical nurse (MDQ-CN | | | Not considered - deemed unsuitable based on initial screening of the tools. |

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| MD assessment questionnaire (MDAQ) ethics stress scale (ESS) stress of conscience questionnaire (SCQ) |

**Appendix N:** Tools Identified and Considered to Measure Burnout/Compassion Fatigue/Professional Quality of Life

| ***Outcome*** ***BURNOUT & COMPASSION FATIGUE (PROFESSIONAL QUALITY OF LIFE)*** | ***Initial Considerations*** | ***Acceptability and Utility*** | ***Measurement Properties*** | ***Selected/ Not Selected Why?*** |
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| ***Burnout Assessment Tool (BAT)***<br><br>*(Schaufeli, Desart and De Witte, 2020)* | The **Burnout Assessment Tool** (BAT) is a new self-report questionnaire developed to measure burnout. It addresses conceptual, technical and practical limitations identified in the Maslach Burnout Inventory (MBI).<br><br>It measures burnout as a state of mental exhaustion that manifests itself as both the inability and unwillingness to spend effort at work.<br><br>Measures:<br>**Core symptoms**<br>Exhaustion – 8 items<br>Mental distance- 5 items | The BAT can be used individually for burnout assessment as well collectively in organisations for screening and identifying those with elevated burnout levels.<br><br>In addition to the full version of the BAT with 23 items, a shortened version with 12 items is also available.<br><br>The items of the shortened version were selected using Rasch analysis. The psychometric properties of the BAT-12 (i.e., factorial validity, internal consistency, test-retest reliability, and convergent and discriminant validity) are similar to that of the full version. | **Validity:**<br>The BAT shows the expected similarity with other burnout questionnaires, including the MBI (convergent validity. Furthermore, burnout, as measured by the BAT, can be distinguished from work engagement, boredom, and workaholism.<br><br>The content validity of the BAT is confirmed by the fact that its subscales, as well as its total-score are, as expected, positively associated with job demands, such as role conflict and bureaucracy and negatively associated with job resources, such as | Not Selected<br>• Very recent tool that has not been widely used or validated in healthcare professional populations.<br>• Measures only burnout-related symptomatology and does not assess compassion satisfaction or secondary traumatic stress. |

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| | Emotional impairment – 5 items<br>Cognitive impairment- 5 items<br><br>**Secondary symptoms**<br>Psychological distress – 6 items<br>Psychosomatic complaints- 5 items | The BAT-12 demonstrates comparable psychometric performance to the full version and is suitable for screening and monitoring purposes.<br><br>**Administration:** Approximately 5 minutes to complete.<br>The BAT was developed for the general workforce and has not been specifically validated for healthcare professionals, although it has been administered in palliative care populations.<br><br>**Scoring:** All items are added and averaged to obtain the total score, which ranges between 1 and 5.<br>A score higher than 3 indicates burnout. | person-job fit and team atmosphere.<br>BAT-scores are also related to organisational outcomes, such as turnover intention and absenteeism, and with personality traits such as neuroticism.<br><br>**Reliability:**<br>The BAT demonstrates excellent internal consistency (Cronbach's α for core symptoms = 0.96) and good test-retest reliability; however, inter-rater reliability is weaker, particularly for subscales. | |
| ***The Copenhagen Burnout Inventory***<br><br>*(Kristensen* et al*., 2018)* | In the CBI burnout is measured as fatigue and exhaustion.<br><br>Based on Schaufeli and Greenglass (2001) definition of burnout as ''a state of physical, emotional and mental exhaustion that results from long-term | 19 items 10 minutes to administer. Has been administered to HCPs as an online survey.<br><br>**Scoring:** Items are averaged within each sub scale to produce a score ranging from 0-100.<br><br>Available free online. | **Reliability:**<br>The CBI demonstrates high internal reliability and excellent internal consistency across clinical settings. Criterion validity is supported by strong correlations with convergent measures (e.g., SF-36 vitality) and weak correlations with divergent | Not Selected<br>• This is a widely validated instrument and is particularly well suited to assessing burnout in healthcare contexts, given its emphasis on the emotional impact of working with clients<br>• This tool would have been strongly considered if |

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| | involvement in work situations that are emotionally demanding''.<br><br>**Three subsections:**<br>Personal burnout<br>Work-related burnout<br>Client related burnout<br><br>Validated in various groups of HCPs from hospital based to community. | CBI has been translated into 8 different languages (e.g., English, German, French, Spanish, Chinese and Korean) and utilised in several countries, and has been accepted as a very robust outcome measure. | measures (e.g., general health and client-related burnout). Concurrent and predictive validity is demonstrated by associations with job satisfaction, sickness absence, sleep problems, medication use, and intention to quit over three years. The CBI accurately detects changes in burnout over time and differences between professional groups. (e.g. Higher levels of work and client burnout in hospital staff). | burnout had been the sole focus of the study. |
| ***The Oldenberg Burnout Inventory***<br><br>*Demerouti, Bakker, Kantas, and Vardakou (2002)* | The OLBI provides scores on two scales: "exhaustion" and "disengagement".<br><br>Exhaustion is conceptualised as a long-term consequence of prolonged exposure to intensive physical, affective, and cognitive strain, and disengagement as distancing oneself from one's work, with negative | **Administration:**<br>16 items, measured on a four-point likert scale 1 – strongly agree – 4 strongly disagree.<br><br>Suitable to administer as an online survey.<br><br>**Scoring:**<br>3 individual scores – exhaustion sub score, disengagement sub score and overall score.<br>Higher scores indicate higher levels of burnout. | **Results from English translation validation study:** (Validated in a sample of 'generalised working adults' and 'fire department employees' in the US – not specifically validated in a sample of HCPs.<br><br>**Internal consistency -** Overall, the internal consistency of the OLBI was acceptable; with scores | Not Selected<br>• Not specific to a healthcare professional population and has not been widely validated in this population<br>• Cut off scores are not available to determine levels of burnout |

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| | attitudes toward work object or content, or work in general.<br><br>The most current version of the OLBI features questions that have balanced positive and negative wording.<br><br>It is not restricted/ specific to human service professions, with questions that apply to any occupational group.<br><br>The Job Demands-Resources model underlying the OLBI views the personal accomplishment/ professional efficacy dimension as less fundamental to burnout. | Scores are interpreted relative to the distribution within the sample, as there are no established normative cutoffs.<br><br>The OLBI does not specify cutoffs for diagnosing burnout, or expected values of exhaustion and disengagement scores (or their difference), for any large, broadly representative normative population. | ranging from 0.74/0.87, All Cronbachs alphas were over 0.70.<br><br>**Test re-test reliability:** The OLBI scores between time 1 and time 2 were moderately correlated.<br><br>**Factorial Validity** – OLBI demonstrates two a priori measurement factors, exhaustion and disengagement. There was relatively more support for the two-factor structure (as compared to a unidimensional model of the OLBI.<br><br>**Construct Validity:** There was also relatively more support for the convergence and divergence of the OLBI and MBI-GS using a MTMM framework. Sufficient convergent and divergent validity. | |
| ***Compassion Fatigue/Satisfaction Self- Test*** | First scale devised by Figley and Stamm. | 66 Item Scale | N/A | Not Selected: |

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| ***(CFST)*** *(Figley, 1995)* | Original measure of compassion fatigue; later revised due to psychometric limitations. Superseded by ProQOL, which better reflects positive and negative aspects of professional quality of life. | | | • Outdated assessment tool more recent versions available |
| ***Compassion Fatigue Scale-Revised***<br><br>*(Gentry et al, 2002 in Figley CR, ed. Treating compassion fatigue)* | Gentry et al in (2002) suggested that CF comprised secondary traumatic stress/CF and burnout. They removed some items from the CFST and developed the Compassion Fatigue Scale-Revised (CFS-R), which has been used in many | 30 items<br><br>Professionals are asked to rate each item on a scale from 1 = rarely/ never to 10 = very often. | N/A | Not Selected:<br>• Outdated and has been replaced by more recent and psychometrically improved versions. |
| ***Compassion Fatigue – Short Scale***<br>*(Adams, Boscarino and Figley, 2014)* | Adams et al. revised the scale again in 2006 to develop the Compassion Fatigue (CF)-Short Scale, which consists of two subscales: secondary trauma (ST) and job burnout (JB).<br><br>It was initially developed to assess compassion fatigue in Social Workers affected by 9/11. | 13 items<br><br>The survey asked respondents to consider each item and indicate how closely it currently reflects their experience, using a 10-point, visual analogue–type Likert scale (rarely/never=1 to very often=10).<br><br>The obtainable scores on the scale range between 13 and 130 and the level of compassion fatigue increases as the score increases. | 13-item short form measuring burnout and secondary traumatic stress. Strong internal reliability (α = 0.90). Validated primarily in social workers; translated versions show good reliability. Limited recent psychometric data for the English version. | Not Selected:<br>Outdated and has been replaced by more recent and psychometrically improved versions. |

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| | The Compassion Fatigue--Short Scale assesses emotional exhaustion related to working with traumatised individuals, conceptualised as compassion fatigue. This is a short form of Figley's (1995) 30-item Compassion Fatigue (CF) Scale - Revised (Gentry et al., 2002). | | | |
| ***Compassion Fatigue Inventory*** *(Eng, Nordström and Schad, 2021)* | A new tool developed in 2020, has not been widely used in research to date.<br><br>Developed by a Swedish researcher and translated to English.<br><br>Designed to measure compassion fatigue exclusive of Burnout and STS. Items were deliberately differentiated from those used in burnout and secondary traumatic stress measures.<br><br>Defined as a first step towards developing a measure to assess | 27 items,<br>Answers are given on a 5-point Likert scale where 1 = “Does not fit at all,” 2 = “Fits poorly,” 3 = “Fits partially,” 4 = “Fits fairly well” and 5 = “Fits perfectly”. | Tested in a group of 655 Swedish clinical psychologists.<br><br>Final version of the scale had excellent internal reliability (α = 0.906).<br><br>There were no significant differences found for CFI scores based on gender or age.<br><br>CFI has a significant strong positive correlation with the CBI Work/Personal factor and with STSS, indicating that the constructs are highly related. | Not Selected –<br><br>• Limited existing evidence base.<br>• Newly developed measure with limited uptake in healthcare research.<br>• Validation to date has been largely restricted to the psychology profession |

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| | compassion fatigue in psychologists. | | Findings suggest that reduced compassion may overlap with burnout but can also be present independently of burnout in psychologists. | |
| ***The Secondary Traumatic Stress Scale (STSS)*** *(Bride* et al.*, 2004)* | Initially developed for the assessment of secondary traumatic stress (STS) in social workers.<br><br>STS operationalized as intrusion, avoidance, and arousal symptoms from indirect exposure to traumatic events via professional relationships.<br><br>Items specifically target exposure to patients/clients.<br><br>The scale has three subdimensions: Intrusion, Avoidance, and Arousal. | The STSS is a 5-point Likert-type assessment tool with 17 items. Participants rate how frequently they experienced each symptom in the past 7 days.<br><br>Each of the STSS items corresponds to one of the 17 PTSD symptoms listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.<br><br>The obtainable scores on the scale range between 17 and 85 and high scores indicate a high level of exposure to STS. | First validated in a sample of masters- level social workers in the US.<br><br>**Reliability:** alpha levels for the STSS and its subscales were as follows: Full STSS (α = 0.93), Intrusion (α = 0.80), Avoidance (α = 0.87), and Arousal (α = 0.83).<br><br>**Convergent and Discriminant validity:** Significant correlations were found between the STSS and its subscales and convergent measures, with no significant correlations observed with discriminant measures, supporting both the convergent and discriminant validity of the STSS.<br><br>**Factorial validity:** The selected fit indices are consistent in their reflection | Not Selected –<br>• Assesses secondary traumatic stress only and does not capture broader dimensions of professional quality of life. |

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| | | | of a good-fitting model, the factor loadings are statistically significant and of sufficient size, and the squared multiple correlations are reasonable. | |
| ***Professional Quality of Life Scale - Version 5 (ProQol- 5)*** *(Stamm, 2010)* | The Professional Quality of Life Scale (ProQOL) is a 30 item self-report questionnaire designed to measure compassion fatigue, work satisfaction and burnout in helping professionals (including healthcare professionals).<br><br>The ProQOL measures three aspects of professional quality of life:<br>Compassion Satisfaction (pleasure you derive from being able to do your work well)<br>Burnout (exhaustion, frustration, anger and depression related to work)<br>Secondary Traumatic Stress (impact of work related primary or secondary trauma)<br><br>Most commonly used measure of Compassion | Administration: 30 items<br><br>Administration typically takes 10-15 minutes to complete.<br><br>Has been administered as an online survey to many different groups of healthcare professionals.<br>translations available for the ProQOL 5 in 28 languages.<br><br>**Scoring:** A number of the items on the scale are reverse scored.<br><br>**Compassion Satisfaction:** Score below 23 indicates low levels of CS (alpha score reliability 0.88)<br><br>**Burnout:** Score below 23 indicates low levels of burnout and score above 41 indicates high levels of burnout (alpha score reliability 0.75) | **Validity:**<br>There is good construct validity with over 200 published papers.<br><br>ProQOL-5 has been tested across multiple populations including nurses and palliative care workers.<br><br>**Reliability:**<br>With respect to the individual inter-item correlations, the CS scale inter-item correlations were reasonable (significant) and there are some concerns with both the BO and STS scales. This pattern was consistent across all three datasets.<br><br>The reliability of the three scales was calculated using both standard methods, Cronbach's alpha and composite reliability, each | Selected<br>• Measures both positive and negative dimensions of professional quality of life, which aligned closely with the aims of this study.<br>• One of the most comprehensive instruments available, capturing burnout and secondary traumatic stress, both of which were identified in the qualitative phase as key impacts of MND care on professionals.<br>• Provides both cut-off thresholds and continuous scores, enabling robust statistical analysis and meaningful interpretation of findings.<br>• Quick and easy to administer, with extensive validation in healthcare populations, facilitating |

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| Fatigue, Of the 100 published research papers on compassion fatigue, secondary traumatic stress and vicarious traumatization, nearly half have utilised the ProQOL or one of its earlier versions. | **Secondary Traumatic Stress:**<br>Scores above 43 indicate high levels of STS<br><br>**Cut Off Scores:**<br>The ProQOL measure is best used in its continuous form. However, many people prefer to have cut scores to indicate relative risks or protective factors. The cuts are set around the 25th and 75th percentiles based on the databank.<br>*"Please note that while we provide cut scores based on the 75th percentile, we do not recommend that the measure be used for anything other than screening, and we prefer from a statistical perspective, to use the continuous numbers."*<br>The most important aspect about interpreting the ProQOL is that it is not a diagnostic test. There are no official diagnoses in the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) or in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000). | scale displayed reliability values in excess of 0.70, the recommended minimum for confirmatory studies. Providing evidence supporting the reliability of the ProQoL 5's three scales.<br><br>**Validity:**<br>**Convergent validity:**<br>Convergent validity was adequate for Compassion Satisfaction, but slightly below the thresholds for Burnout and Secondary Traumatic Stress.<br><br>**Construct validity:** In this test, the three ProQoL 5 scales and their relation to the DASS depression, anxiety and stress scales were determined. The correlations between all three of the ProQoL 5 scales and the DASS scales were all significant and in the expected direction, demonstrating construct validity of all three scales. | comparison with similar professional groups. |

**Appendix O:** Tools Identified and Considered to Measure Resilience and Coping

| *Outcome*<br><br>***RESILIENCE AND COPING*** | *Initial Considerations* | *Acceptability and Utility* | *Measurement Properties* | *Selected/ Not Selected Why?* |
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| ***The Resilience Scale (RS-25) and short version (RS-14)***<br><br>*Wagnild & Young (1993)* | The first reported scale to measure resilience.<br><br>Has been translated into many languages and widely used in research worldwide. It can be used in any setting and is applicable to almost any age group with studies containing participants ranging from adolescents to older adults.<br><br>It aims to identify the degree of individual resilience (personal competence and acceptance of self and life); or the inner strength required to adapt positively.<br><br>A 14-item version was developed by the authors in 2003 (RS-14) to fulfil many researchers preference for a | $75 to purchase, with user guide and can be administered as an online survey.<br><br>7-point likert scale:<br>1= strongly disagree<br>4= neutral<br>7 = strongly agree<br><br>No descriptor provided for other numbers on the scale.<br><br>Higher scores reflect higher levels of resilience.<br><br>Data ranges are suggested and are categorised as low, medium and high levels of resilience. | Cronbach's α ranges from 0.87 to 0.95.<br><br>The psychometric properties of this tool have been widely studied in a range of different contexts and overall demonstrate good internal consistency, construct validity and concurrent validity.<br><br>**Limitations:**<br>Items are all worded positively and keyed in the same direction.<br>Likert scale with only 2 descriptors. | Not Selected<br>• Lengthy and vague Likert scale.<br>• Too many items for current survey.<br>• Does not include or measure coping abilities r styles.<br>• Not specific to healthcare context. |

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| | shorter instrument. This version is strongly correlated with the 25-item version. | | | |
| ***The Connor Davidson Resilience Scale (CD-RISC- 25)***<br><br>*Connor & Davidson (2003)*<br><br>*Revised and condensed by (Cambell, Sills & Stein, 2007) to* ***CD-RISC-10*** *(10 item)*<br><br>***CD-RISC-2*** *also available* | The Connor-Davidson Resilience measure is a self-rated assessment of stress coping ability. It is one the most widely used scales measuring psychological resilience.<br><br>The scale was developed based on concepts of hardiness, adaptation, and stress endurance.<br><br>Initial factor analyses identified five factors:<br>1) Notion of personal competence, high standards and tenacity.<br>2) Trust in one's instincts, tolerance of negative affect, and strengthening effects of stress.<br>3) Positive acceptance of change, and secure relationships.<br>4) Control.<br>5) Spiritual influences. | Permission to use must be obtained from the authors and there is an associated fee.<br><br>**Administration**: The 25-item scale can be completed in approx 5 - 10 minutes unless there are complicating factors. The 10 and 2 item scales take between 1 and 5 minutes to complete.<br><br><u>Scoring:</u><br>Participants are asked to reflect on how much the statements apply to them over the last month.<br><br>5-point likert scale,<br>not true at all=0,<br>rarely true=1,<br>sometimes true=2,<br>often true=3,<br>true nearly all of the time=4. | The CD-RISC has been tested in the general population, as well as in clinical samples, and demonstrates sound psychometric properties, with good internal consistency and test–retest reliability.<br><br>**Internal consistency-** Cronbach's for the full scale is α = 0.89.<br><br>**Test re-test reliability-** demonstrated a high level of agreement between time 1 and 2, with an intraclass correlation coefficient of 0.87.<br><br>**Convergent validity -** CD-RISC scores were positively correlated with the Kobasa hardiness measure in psychiatric outpatients, compared to the Perceived Stress Scale (PSS-10), the CD-RISC showed a | Not Selected<br>• The shorter versions of the CD-RISC scale were strongly considered for this current study.<br>• The CD-RISC-2 was felt to be too brief and a number of items on the CD-RISC-10 were not felt to be too vague or not relevant for the current study population i.e. 'I am not easily discouraged by failure'.<br>• There were a number of items that were however felt to be relevant for this study such as 'I try to see the humorous side of things' and 'I am able to adapt when changes occur'.<br>• The 25-item version was too lengthy for the current study. |

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| | The decision as to which of the three versions to use is usually guided by the time available, and a judgement as to what kinds of information need to be obtained. For example, items relating to spirituality and faith are to be found only in the 25-item scale. For a very brief measure, such as an early screen or a lengthy questionnaire where "space" is at a premium, the 2-item scale may be most suitable. For a factorially homogeneous scale which focuses mainly on hardiness, the 10-item scale is particularly suitable. | Total sum scores range between 0-100, with higher scores indicating greater perceived resilience.<br><br>For the CD-RISC-10, the total score ranges from 0-40, and for the CD-RISC-2, it ranges from 0-8. | significant negative correlation indicating that higher levels of resilience corresponded with less perceived stress. | |
| ***Baruth Protective Factors Inventory***<br><br>*(Baruth & Carroll, 2002)* | The Baruth Protective Factors Inventory identifies presence of four primary protective factors:<br><br>1. Adaptable personality,<br>2. Supportive environment,<br>3. Fewer stressors,<br>4. Compensating experiences. | **Administration:**<br>Number of items: 16<br>Response options: 5 - point scale responses, including strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree.<br><br>**Scoring:**<br>Total score: Individual scale scores and total | Psychometrically tested in a group of undergraduate human development students in the US. Homogenous young female sample.<br><br>**Reliability:** Internal consistency of overall scale (α = 0.83). | Not Selected<br>• Not felt to be very relevant to work related resilience, factors more applicable to measuring personal resilience.<br>• Not widely used in health service research.<br>• Protective factors are an area of interest for this research; however this tool was not felt to measure the |

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| | These are based on the literature relating to resilience or adaptation in the face of difficulties. | sum scores are calculated, for a range of 4-16 on each scale and a range of 16-80 on the total score.<br><br>Individual items are coded so most resilient responses receive a score of 5 and the least resilient responses receive a score of 1. | **Construct Validity –** Convergent and divergent validity was indicated by validity co-efficients falling in the predicted direction when compared to other relevant scales. | relevant protective factors (work-related factors).<br>• Tools that measure resilience and coping capacity were the priorities for this study. |
| ***Brief Resilience Scale***<br>*(Smith et al, 2008)* | The Brief Resilience Scale was created to assess the perceived ability to bounce back or recover from stress.<br><br>The scale was developed to assess a unitary construct of resilience and it includes both positively and negatively worded items. It is a useful outcome measure to measure resilience in the context of stress but has a very narrow focus. | **Administration:** Number of items: 6, Items 1, 3, and 5 are positively worded, and items 2, 4, and 6 are negatively worded.<br><br>5-point scale response, 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree<br><br>**Scoring:** Responses varying from 1-5 are added for all six items giving a score range from 6-30. | The BRS was tested on four samples. Sample 1 consisted of 128 undergraduate students. Sample 2 consisted of 64 undergraduate students. Sample 3 consisted of 112 cardiac rehabilitation patients. Sample 4 consisted of 50 women who either had fibromyalgia (n = 20) or were healthy controls (n = 30). All four samples were recruited from a medium sized metropolitan area in the U.S.<br><br>**Internal Consistency:** Internal consistency was good, with Cronbach's | Not Selected<br>• Narrow focus on resilience as the ability to bounce back from stress.<br>• Does not measure coping, adaptability, protective factors.<br>• Strong focus on bouncing back from stress may not capture the coping/ resilience traits of those who are not currently or have not experienced work-related stress. |

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| | | The total sum is divided by the total number of questions answered.<br><br>**Interpretation:**<br>1.00 - 2.99- low resilience<br>3.00-4.30- normal resilience<br>4.31-5.00- high resilience. | alpha ranging from α = 0.80–0.91.<br><br>**Test re-test reliability:** of 0.69 for one month & 0.62 for three months.<br><br>**Convergent Validity:** The BRS was positively correlated with the resilience measures, optimism, and purpose in life, and negatively correlated with pessimism and alexithymia.<br><br>**Discriminant Predictive Validity:** The BRS was negatively related to perceived stress, anxiety, depression, negative affect, and physical symptoms. | |
| ***Predictive 6 Factor Resilience Scale***<br>*(Rossouw, 2018)* | The Predictive 6-Factor Resilience scale is based on a neurobiological model of resilience domains, focusing on the potential bidirectional relationship between resilience and health, physical functioning, and longevity.<br><br>Key factors include: | 16 items<br><br>**Scoring:**<br>5-point scale ranging from:<br>1=not at all like me,<br>2=a bit like me,<br>3=somewhat like me,<br>4=often like me, and<br>5=very much like me | Limited psychometric testing has been completed to date and the tool has not been widely used in research in comparison to other widely used and validated measures of resilience. | Not Selected<br>• Items are felt to be more relevant to personal resilience than work related resilience in a healthcare setting. Some items are quite vague and related to general well-being such as sleep, exercise and diet habits. Not felt to be relevant to |

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| • Vision (including self-efficacy and goal setting),<br>• Composure (including emotion regulation and ability to recognise, understand and act on internal prompts and physical signals),<br>• Tenacity (including perseverance and hardiness),<br>• Reasoning (including cognitive traits like problem-solving, resourcefulness, and thriving),<br>• Collaboration (including psychosocial interaction),<br>• Health (including physiological health – incorporating regular exercise, nutrition and sleep hygiene).<br>• A final factor of momentum is also assessed, measuring approach and avoidance in terms of | Average scores are calculated within each domain, and the overall average score across all domains is used to determine overall resilience score.<br><br>Comprehensive scoring manual provided with normalisation scores for the general population. | the aims of this current study.<br>• Complex scoring procedure: The PR6 includes six distinct factors that need to be scored and interpreted individually. This can make the scoring and interpretation process more complex compared to simpler one-dimensional resilience scales.<br>• Has not been widely used in research to date or with similar populations as the current study. |

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| | a sense of direction and openness to new challenges. | | | |
| ***Resilience Scale for Adults***<br><br>*(Friborg et al, 2003 & revised in 2005 by the same author)* | This tool was designed to measure resilience in adults by focusing on protective factors that promote resilience, the six protective domains are personal competence, social competence, family cohesion, social support, personal structure, and external resources. | **Administration:**<br>Number of items: 33<br>Response options: 7-point scale assessing the degree of agreement, 1=disagree to 7=agree<br><br>**Scoring:**<br>Total score: Total sum scores are calculated, and all items are positively worded, potential scores range from 25 to 175 with higher scores indicating higher resilience. | Psychometrically tested with a random sample from the general population, has not been widely used or tested with individuals who have successfully adapted and dealt with long-term stress and difficulties. Not commonly used in clinical settings.<br><br>Low-to-moderate intercorrelations between the subscales of the RSA mean that the dimensions should be regarded as subscales measuring different, but all various and positive aspects of the concept of resilience. Current research does not strongly support the summing of the RSA items as a single score.<br><br>The internal consistency of the RSA subscales was high and the item-total correlations for all subscales were moderate to | Not Selected<br>• Too lengthy for the current study<br>• Focuses on protective factors for resilience and not on the aspects of resilience of interest for this study such as emotional regulation, problem-solving skills or the ability to adapt to adversity.<br>• Not relevant for those who have dealt with or experienced significant stressors.<br>• Does not provide unidimensional resilience score, recommended to interpret sub-scales independently. |

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| | | | high, indicating adequate reliability. | |
| ***The Protective Factors for Resilience Scale*** *(Harms et al., 2017)* | The Protective Factors for Resilience Scale (PFRS) Is a self-report measure designed to assess key individual and interpersonal protective factors that support psychological resilience. It typically evaluates domains such as personal competence, social support, coping resources, and adaptive beliefs, providing an overview of strengths that may buffer against stress and adversity. | Number of items: 20<br>Response options: 7-point response scale, 1=strongly disagree to 7=strongly agree<br><br>Total score: responses are summed within each subscale and for the total measure. | Psychometrically tested with students in Australia and a random sample from the population. Not specific for use in a clinical or healthcare context.<br><br>The pattern of associations between the scores on the PFRS, various coping styles, self-esteem and life satisfaction provided good initial evidence regarding the construct validity of the PFRS. | Not Selected<br>• Too lengthy for the current study<br>• Also focuses on protective factors for resilience and not on how individuals respond, adapt or cope with stress.<br>• Significant emphasis on support from friends and family – (professionals reported to most often get support from colleagues in this context) |
| ***Rushton Moral Resilience Scale*** *(Rushton, 2021)- Revised Moral Resilience Scale (Rushton et al., 2024)* | The revised version was reviewed and considered for this study due to its applicability for an interprofessional population, succinctness, and improved psychometric properties.<br><br>Moral resilience is defined as "*the capacity of an individual to sustain or restore their integrity in response to moral adversity*," has been | Registration is required to use the scale and detailed scoring instructions are then provided. There is no cost associated with use.<br><br>There are four sub-scales with four items each (16-items in total) | Tested and validated on a large sample of interdisciplinary healthcare workers, therefore very relevant and applicable for the current study sample.<br><br>Overall scale reliability (α = 0.86).<br><br>Higher moral resilience was associated with lower perceived stress, anxiety, | Not Selected<br>• Too narrowly focused on resilience in the face of moral distress and ethical challenges. This is a very specific definition or type of resilience, which may not capture more general aspects of resilience unrelated to moral conflict.<br>• Potential for overlap and confusion with the |

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| | proposed as a resource to address moral suffering while contributing to well-being. The RMRS was developed to measure this specific type of resilience. | • Responses to moral adversity,<br>• Personal integrity,<br>• Relational integrity<br>• Moral efficacy<br><br>Items are rated on the response scale:<br>1 (disagree),<br>2 (somewhat disagree),<br>3 (somewhat agree),<br>4 (agree). | depression and moral distress.<br>The revised RMRS-16 offers a valid and reliable instrument to assess not only the negative impact of confronting moral adversity but also individual moral capabilities and strengths. | measurement of moral distress in this study. |
| ***Brief COPE***<br>*(Carver, 1997)* | A brief form of a previously published measure called the COPE inventory (Carver 1989). Previously included 60 items – Brief COPE reduced to 28.<br><br>Designed to measure both adaptive coping strategies (e.g., active coping, positive reframing) and maladaptive strategies (e.g., denial, substance use, self-blame). | 14 sub-scales with two items each.<br>• Denial<br>• Substance Use<br>• Emotional Support<br>• Instrumental Support<br>• Behavioral Disengagement<br>• Venting<br>• Positive Reframing<br>• Planning<br>• Humour<br>• Acceptance<br>• Religion<br>• Self-Blame<br><br>Scored on a 1-4 Likert Scale. 1 (I haven't been | **B**rief COPE has been widely used in various research and clinical settings to assess coping strategies.<br><br>The subscales of the Brief COPE show moderate to good reliability**,** with Cronbach's alpha values generally ranging between 0.50 and 0.90.<br><br>Adequate test-retest reliability in short intervals,<br><br>Good construct, convergent, and discriminant validity, but factor structures may vary across populations. | Not Selected<br>• Too lengthy for current study<br>• Questions are very specifically worded for people who have experienced stress or adversity and less relevant for those who have not e.g. '*I've been making jokes about it*', '*I've been expressing my negative feelings'*. These questions are not suitable for participants who are not experiencing negative emotions from their work.<br>• No overall score of coping ability provided, subsections scored and interpreted individually. |

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| | | doing this at all) to 4 (I've been doing this a lot).<br><br>High scores on adaptive subscales indicate that the individual is using healthy, effective strategies to cope with stress.<br><br>High scores on maladaptive subscales suggest that the individual is engaging in potentially harmful ways of dealing with stress, which may exacerbate emotional distress or prevent problem resolution.<br><br>No overall score of coping ability provided, subsections are interpreted individually. | | An aggregate score of coping/ resilience was required for this study. |
| ***Brief Resilient Coping Scale***<br><br>*(Sinclair & Wallston, 2004)* | The Brief Resilient Coping Scale captures tendencies to cope with stress adaptively. The scale focuses on the tendency to effectively use coping strategies in flexible, committed ways to actively | **Administration:**<br><br>Number of items**:** 4<br><br><u>Response options</u>: 5-point scale response, ranging from | The validity and reliability data for the Brief Resilient Coping Scale (BRCS) was originally reported using two samples of individuals with rheumatoid arthritis. | Selected<br>• Brevity and short time to complete – reduce respondent fatigue.<br>• Ability to calculate a total/ aggregate score of resilience and relevant cut off scores provided to |

solve problems despite stressful circumstances.

The themes that are captured by the BRCS are tenacity, optimism, creativity, an aggressive approach to problem solving, and a commitment to extract positive growth from difficult situations. Each of these were identified as important for working in this clinical area by professionals during the qualitative phase of this research.

Sinclair & Wallston (2004) also suggest that individuals who endorse these four items are expected to be goal directed, believe in their ability to address adverse circumstances, and usually succeed at their selected challenges, again important attributes identified by participants in the qualitative phase of this research.

The BRCS also describe an effective, active problem-

1=does not describe me at all to 5=describes me very well. Descriptors provided for each numerical rating.

**Scoring:**
Total sum scores range from 4 to 20.

**Interpretation:**
Scores of
4-13 indicate low resilient coping,
14-16 indicate medium resilient coping,
17-20 indicate high resilient coping.

Individuals who score high on the BRCS exhibit a tendency to reframe the potency of stressors by affirming control of positive ways to offset potential losses/ perceived failings.

The scale has however more recently been used in studies of healthcare professionals, in particular during and after the COVID-19 pandemic.

The BRCS has adequate internal consistency and test-retest reliability. Convergent validity of the scale is demonstrated by predictable correlations with measures of personal coping resources (e.g., optimism, helplessness, self-efficacy), pain coping behaviours,
and psychological well-being.

Cronbach's alphas from the original study ranged from 0.64 to 0.71 in different administrations with a test–retest reliability of $r = 0.71$ ($p < 0.001$).

The BRCS meets the minimal standard (~ 0.70) for reliability of a research instrument. The brevity of this 4-item scale is a

differentiate between different levels of resilient coping (low, medium, high).

- Measures the elements of resilience and coping identified as important by participants in the qualitative phase of this research, including positive coping strategies**,** such as problem-solving and maintaining a positive outlook and emotional intelligence or regulation.
- Adequate psychometric properties for a short outcome measure/scale.
- Measures situational patterns associated with resilience and takes a view of resilience as an adaptive process which is particularly relevant for work related stress situations.

solving coping pattern that reflects the resilient coping patterns and a dynamic and complex process of resilience, many of the previous tools more narrowly focus on personality traits and environmental characteristics associated with resilient individuals and very few scales measure or identify resilience and the adaptive nature of coping, that was felt to be important for this current study.

double-edged sword, making the scale convenient to administer although this can affect the internal consistency. Nonetheless, the BRCS has sufficient internal consistency and stability for a 4-item scale (Shelley, 1984).

## **Appendix P:** Cross-Sectional Survey: Letter of Ethical Approval

23/10/2024
Title: Moral Distress, Professional Quality of Life and Resilient Coping in Healthcare Professionals working with ALS/MND: A Cross Sectional Survey

REAMs No: 3500

Dear Megan Walls,

Your application has been reviewed by the relevant Research Ethics Committee (REC) and we are pleased to inform you that the above project has been approved.

Please note that any documents submitted for GDPR purposes in association with your ethics application are approved by the REC from an ethical perspective only (GDPR compliance is assumed, as per your uploaded letter of approval from the DPO).

It is the responsibility of the researcher/research team to ensure that, if applicable, all aspects of the study are executed in compliance with the General Data Protection Regulation (GDPR), the Health Research Regulations, Data Protection Act 2018, particularly regarding the storage and destruction of data arising from the research, and adhere to any relevant Health & Safety regulations.

Please note the reporting requirements outlined, in particular the need for:

- An immediate report of any serious or unexpected adverse event should be sent immediately to your REC via email. The Procedures for Reporting Adverse Events are outlined in the application. The Adverse Event form are available here.
- Any other unforeseen events should also be reported using this form and sent to your REC via email. The Adverse Event form are available here.
- An end of project report is due one year from the end of project date. The form is available here. This should be sent to your REC via email.
- If the data collection period is longer than 1 year, an annual report should be submitted. The form is available here. This should be sent to your REC via email.

You, and your research team (where applicable), are responsible for conducting the research strictly in the manner outlined in your application and supporting documentation, and in compliance with it. Proposed changes or amendments to the approved study must be submitted to the REC for approval in advance of any changes or amendments being implemented. In the event that the changes or amendments are significant, the REC may require a new submission. This ethical approval expires with the end dates of the project as stated in the application.If you have any queries regarding this decision, please contact the Chair of your REC.We wish you all the very best with your research project.

Kind Regards,
The REC

NB. If your study is to be conducted outside TCD, e.g. in a hospital site, please note that Trinity College REC approval does not of itself entitle you to conduct research in an external site. In this regard, the onus is upon you - the researcher, to ensure that all permissions have been obtained, and that any other requirements of the study site have been satisfiedNB. If your study involves a trial of medicinal products or medical devices, apps on humans you must provide a copy of your Clinical Trial Sponsorship from TCD - indicating that you have the appropriate trial insurance and sponsor oversight.

## **Appendix Q:** Checklist for Reporting of Survey Studies (CROSS)

| Section/topic | Item | Item description | Reported on page/Section |
|---|---|---|---|
| **Title and abstract** | | | |
| Title and abstract | 1a | State the word "survey" along with a commonly used term in title or abstract to introduce the study's design. | First page |
| | 1b | Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions. | Abstract |
| **Introduction** | | | |
| Background | 2 | Provide a background about the rationale of study, what has been previously done, and why this survey is needed. | 5.1 Introduction |
| Purpose/aim | 3 | Identify specific purposes, aims, goals, or objectives of the study. | 5.1.1 Aims and Objectives |
| **Methods** | | | |
| Study design | 4 | Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal). | 5.2.1 Study design – cross-sectional online survey |
| Data collection methods | 5a | Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used). | 5.2.3 Question development and measurement tools – alternative tools identified and considered can be found in appendices M-O |
| | 5b | Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any). | 5.2.3 Question development and measurement tools |
| | 5c | Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. | 5.2.2 Survey development |

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| | 5d | Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement). | See Appendix L |
| Sample characteristics | 6a | Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria). | 5.2 Sampling and recruitment. Table 5.2 eligibility/exclusion criteria |
| | 6b | Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied. | 5.2 Sampling and recruitment |
| | 6c | Provide information on sample size, along with details of sample size calculation. | N/A for this exploratory study |
| | 6d | Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys. | N/A for this exploratory study |
| Survey administration | 7a | Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room or by use of online tools, such as SurveyMonkey). | 5.2.5 Survey distribution |
| | 7b | Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days. | 5.2.5 Survey distribution |
| | 7c | Provide information on the entry process:<br>–>For non-web-based surveys, provide approaches to minimize human error in data entry. | N/A online survey. |
| | | –>For web-based surveys, provide approaches to prevent "multiple participation" of participants. | 5.2.5 Survey distribution |
| Study preparation | 8 | Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey). | 5.3.4 Sampling and Recruitment |
| Ethical considerations | 9a | Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate). | 5.2.3 Ethical Approval<br>Letter of ethical approval can be found in Appendix P |
| | 9b | Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access. | 5.2.5 Survey distribution - Targeted distribution was implemented to avoid |

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| | | | unauthorised access |
| | 10a | Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis. | 5.2.6 Data analysis |
| | 10b | Report any modification of variables used in the analysis, along with reference (if available). | N/A |
| | 10c | Report details about how missing data was handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation). | 5.2.6.1 Quantitative Analysis - Missing Data |
| Statistical analysis | 10d | State how non-response error was addressed. | 5.2.6.1 Quantitative Analysis - Missing Data |
| | 10e | For longitudinal surveys, state how loss to follow-up was addressed. | N/A cross-sectional study |
| | 10f | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample. | N/A |
| | 10g | Describe any sensitivity analysis conducted. | N/A |
| **Results** | | | |
| | 11a | Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible. | 4.3.1 Participants |
| Respondent characteristics | 11b | Provide reasons for non-participation at each stage, if possible. | N/A – missing data identified as MCAR |
| | 11c | Report response rate, present the definition of response rate or the formula used to calculate response rate. | N/A |
| | 11d | Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion). | N/A |
| Descriptive results | 12 | Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes. | Table 5.4 Participants information |
| Main findings | 13a | Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values. | Adjusted estimated provided for multivariable |

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| | | | analysis due to exploratory nature of the study and number of comparisons. |
| | 13b | For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate). | 5.2.6.1 Quantitative Analysis – Multivariable analysis |
| | 13c | Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible). | N/A missing data were negligible |
| **Discussion** | | | |
| Limitations | 14 | Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders. | 5.4 Study strengths and limitations |
| Interpretations | 15 | Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research. | 5.4 Addressed throughout discussion section |
| Generalisability | 16 | Discuss the external validity of the results. | 5.4 Discussed throughout discussion section |
| **Other sections** | | | |
| Role of funding source | 17 | State whether any funding organisation has had any roles in the survey's design, implementation, and analysis. | N/A |
| Conflict of interest | 18 | Declare any potential conflict of interest. | N/A |
| Acknowledgements | 19 | Provide names of organisations/persons that are acknowledged along with their contribution to the research. | N/A |

## **Appendix R:** Demographic and Work-related Data for Survey Respondents No Longer Working in an MND Service

**Table**: Demographic and work-related data for *n*= 10 respondents not currently working in a service for individuals living with ALS/MND. (*) = missing data. IQR = Inter-quartile range.

| **Variable** | **N (%)** |
|---|---|
| **Median percentage of Working Week with ALS/MND** | 28 (IQR: 9.5) |
| **Last worked with ALS/MND:** | |
| Last 6 months | 1 (10) |
| 7-12 months ago | 5 (50) |
| 13-18 months ago | 1 (10) |
| 19-24 months ago | 3 (30 |
| **Work Pattern:** | |
| Full Time | 2 (20%) |
| Part Time | 8 (80%) |
| **Profession:** | |
| AHP's: | 9 (90) |
| Dietitian | 2(20) |
| Physiotherapist | 2(20) |
| Psychologist | 1(10) |
| Social Worker | 1(10) |
| Speech and Language Therapist | 3(30) |
| Nursing | 1 (10) |
| **Gender:** | |
| Female | 8 (80) |
| Male | 1 (10) |
| Prefer not to say | 1 (10) |
| **Age Category:** | |
| Under 30 | 0 (0) |
| 31-50 | 8 (80) |
| 51+ | 2 (20) |
| **Country:** | |
| United Kingdom | 5 (50) |
| Ireland | 1 (10) |
| France | 1 (10) |
| Denmark | 1 (10) |
| Italy | 1 (10) |
| Turkey | 1 (10) |
| **Experience Category:** | |
| 0-10 | 5 (50) |
| 11-20 | 3 (30) |
| 21+ | 2 (20) |
| **Left job because of factors related to working with ALS/MND:** | |
| Yes | 1 (10) |
| No | 9 (90) |
| **Heard of MD:** | |
| Yes | 7 (70) |
| No | 3 (30) |
| **Resonate with MD (*)** | |
| Yes | 5 (55) |

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|---|---|
| No | 4 (45) |
| **Median BRCS Score (*)** (*n* = 8) | 15 (IQR: 1.75) |

## **Appendix S:** Frequency and Rank Order of Statements Identified as Most Distressing in the Online Survey

| Rank | Frequency(n) | Statement | Statement |
|---|---|---|---|
| **1** | 82 | 20 | Witness individuals with ALS/MND struggling while waiting for necessary aids, devices, or services. |
| **2** | 72 | 21 | Experience individuals with ALS/MND receiving unequal access to services/resources depending on the region where they live. |
| **3** | 64 | 12 | Feel unable to alleviate the burden on family and informal caregivers because of insufficient time or available services. |
| **4** | 62 | 22 | Witness compromised care for individuals with ALS/MND due to lack of equipment/resources/bed capacity. |
| **5** | 59 | 6 | Have difficulty communicating hope or optimism for individuals with ALS/MND with no available cure for the disease. |
| **6** | 52 | 10 | Witness individuals with ALS/MND in distress or pain due to poorly managed symptoms. |
| **7.5** | 50 | 5 | Feel unable to offer individuals with ALS/MND and their families the emotional support or comfort they need. |
| **7.5** | 50 | 8 | Feel unable to provide an intervention that could benefit the individual with ALS/MND because of cognitive or behavioural changes. |
| **9.5** | 49 | 7 | Worry that the wishes of individuals with ALS/MND are not being respected when problems with their communication arise. |
| **9.5** | 49 | 11 | Struggle to provide the necessary care for someone whose condition is already at an advanced stage when I first meet them. |
| **11** | 47 | 9 | Witness physical care needs that remain unaddressed because of difficulties with psychological adjustment. |
| **12** | 46 | 17 | Witness care for individuals with ALS/MND being negatively affected because of staffing vacancies within a team or service. |
| **13** | 39 | 18 | Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the person's care. |
| **14.5** | 36 | 4 | Feel that by initiating future care planning, I am adding to the individual's psychological distress. |

| | | | |
|---|---|---|---|
| **14.5** | 36 | 16 | Witness compromised care for individuals with ALS/MND because of poor communication between healthcare professionals. |
| **16** | 34 | 14 | Struggle to meet the needs of both individuals with ALS/MND and their family members because of their conflicting priorities or opinions. |
| **17** | 32 | 2 | Feel pressure to provide care/intervention that I don't believe will benefit the individual with ALS/MND at the request of others, such as family, senior colleagues, or other services. |
| **18** | 29 | 19 | Struggle to meet the needs/expectations of individuals with ALS/MND or their families due to limitations imposed by my organisation's policies or procedures. |
| **19** | 27 | 1 | Feel unable to effectively plan for the future care of individuals with ALS/MND because of my uncertainty regarding the trajectory of disease progression. |
| **20** | 25 | 3 | Feel unprepared to engage in future care planning or end-of-life care conversations due to a lack of appropriate training. |
| **21** | 22 | 24 | Be required to care for more individuals with ALS/MND than I can safely care for. |
| **22** | 20 | 23 | Feel restricted to prioritise only certain aspects of care for individuals with ALS/MND due to limited time during appointments. |
| **23** | 17 | 15 | Have difficulty implementing care or interventions without family or informal caregiver support. |
| **24** | 7 | 13 | Feel unable to effectively deliver care for an individual with ALS/MND due to a breakdown in the patient-clinician relationship. |

## **Appendix T:** Pairwise Spearman Rank-Order Correlation Coefficients Between MD Thermometer, ProQOL-5 And BRCS Outcomes.

| | **Resilient Coping (BRCS)** | **Compassion Satisfaction (ProQOL)** | **Secondary Traumatic Stress (ProQOL)** | **Burnout (ProQOL)** |
|---|---|---|---|---|
| **MD Thermometer** | - 0.137* | - 0.248*** | 0.525*** | 0.469*** |
| **Burnout** | -0.308*** | -0.574*** | 0.651*** | - |
| **Secondary Traumatic Stress** | -0.193** | -0.272*** | - | - |
| **Compassion Satisfaction** | 0.367*** | - | - | - |

**<0.05, **<0.01, ***<0.001.*

**Appendix U:** Allied Healthcare Professional Group Sub-Analysis

| **Outcome** | **Occupational Therapy (*n*=23)** | **Physiotherapy (*n*=39)** | **Psychology (*n*=14)** | **Speech and Language Therapy (*n*=22)** | **Kruskal-Wallis Test Results** ($X^2$, p-value) |
|---|---|---|---|---|---|
| | **Median (IQR)** | **Median (IQR)** | **Median (IQR)** | **Median (IQR)** | |
| **MD Thermometer** | 4 | 3 | 2 | 2 | $X^2$ = 0.1615, *p* = 0.162 |
| **ProQOL - Burnout** | 27 | 22 | 23 | 22 | $X^2$ = 29.941, *p* = 0.120 |
| **ProQOL - Secondary Traumatic Stress** | 22 | 21 | 18.5 | 19 | $X^2$ = 28.845, *p* = 0.149 |
| **ProQOL - Compassion Satisfaction** | 39 | 41 | 36.5 | 38.5 | $X^2$ = 15.827, *p* = 0.8626 |
| **BRCS Total Score** | 15 | 15 | 15 | 14 | $X^2$ = 10.666, *p* = 0.299 |

**Appendix V: Full Content Analysis of Helpful and Supportive Factors and Illustrative Quotations Provided by Survey Respondents**

## Extrinsic Work-Related Supports:

**Informal Collegial Support: (*n* = 66)**

This related to reports of unstructured, spontaneous and peer-initiated support that colleagues provided to each other in the workplace. This category includes examples of colleagues supporting each other to process and reflect on the emotional impact of the work and also providing practical assistance or reassurance with complex clinical cases or situations.

**Emotional Support:**

- *'To share personal experiences with colleagues (doctors, nurses, psychologists, social services assistants and other healthcare professionals) discussing also the burden of patients' care'*. (Medical)
- *'Having supportive colleagues with opportunity to talk formally and informally about what we experience'*. (Speech and Language Therapist)
- '*Having people to share the emotional load with, particularly those who get it on a professional level'*. (Speech and Language Therapist)
- *'Talking to colleagues that understand'* (Nurse)
- *'I find it helpful to discuss difficult or sad situation with colleagues'* (Nurse**)**
- The other members of my team are the only support I have for my emotional well-being at work, and they are invaluable (Care coordinator)

**Practical Support:**

- '*Sharing doubts and experiences about patients with colleagues who work in this field'* (Medical)
- *'Enough opportunities to discuss the issues with colleagues'* (Medical)
- *'I have good colleagues to talk to and evaluate patient visits'* (Physiotherapist)
- '*Sharing challenging situations with colleagues who work with ALS/MND'* (Psychologist)
- *'Discuss with colleagues situations that may cause us difficulties with patients'* (Nurse)

**Working in a Supportive Multidisciplinary Team Environment: (*n* = 63)**

This related to working within an effective and supportive multidisciplinary team where there were positive working relationships. This category supports the idea that no one professional can take on the care of an individual living with MND alone, and that integrated and collaborative MDT working is required to both deliver effective care and support the healthcare professionals providing that care. This category included examples of teamwork for collaborative care planning, decision making, joint working and team learning or reflection.

- **'***MDT working with good communication'* (MND Coordinator)
- *'Discussion with team/difficult cases/how to do better'* (Nurse)
- *'When there are team meetings. discussions and support'* (Occupational Therapist)
- *'Good teamwork with my colleagues, where we support each other in difficult situations'*.(Medical)
- *'A supportive and positive team of colleagues working towards similar goals'* (Nurse)

- *'Working as a team, having medical and non-medical healthcare professionals around to talk about difficult cases and situations'* (Meidcal)
- *'The collaboration between all professionals, that is essential'* (Occupational Therapist)

**Structured Team Reflection and De-Briefing: (*n* = 15)**
**R**espondents identified also benefiting from more structured or planned team reflection or debriefing sessions.

- '*Having a strong team around you, where debriefing after a consultation takes place, can make a significant difference'* (Physiotherapist)
- *'Debriefs with the team'* (Physiotherapist)
- *'Reflective sessions with our team'* (Physiotherapist)
- '*Debriefing sessions on individual cases'* (Physiotherapist)

**Access to Clinical Supervision: (*n* = 21)**
21 respondents reported that they either did benefit or would benefit from access to good quality clinical supervision. Some respondents identified receiving this support from senior colleagues or management, while *n* = 2 reported accessing supervision from peers, '*I set up peer supervision for psychology colleagues, and this has been invaluable'* (Psychologist).

- *'1:1 clinical supervision'* (Psychologist)
- *'Formal supervision would be useful*' (Nurse)
- *'Good supervision sessions*' (Occupational Therapist)
- '*We have supervision at work, that is helpful'* (Physiotherapist)
- *'Good quality clinical supervision'* (Psychologist)

**Psychology Support (*n* = 7)**
7 respondents reported benefiting from access to psychology support for supervision, team reflection sessions or caseload discussions.

- ***'**We have supervision sessions with a psychologist which help'* (Nurse)
- *'Support from our team psychologist to discuss caseload*' (Nurse)
- '*Our psychologist on our team has started running reflective practise sessions'* (Speech and Language Therapist)
- *'Psychology supervision is provided monthly through work as a group session'* (Occupational Therapist)

**Relevant Training Opportunities: (*n* = 7)**
7 respondents identified that they did or would find it helpful to avail of relevant training opportunities, to help them stay informed and up to date with new evidence, advancements or effective practices to support plwMND.

- *'Shared learning events'* (MND Coordinator)
- '*Attending relevant training'* (Psychologist)
- *'To feel confident as a clinician, I need to remain up to date with effective practises'* (Speech and Language Therapist)
- *'Training (we have too little of it)'* (Occupational Therapist)

- '*Training that focuses on more than the understanding of MND but focuses on psychological management, communication skills, awareness of the wider MDTs role'* (Dietitian)

**Support from National MND Charity Organisations and International Groups: (n = 3)**
*3* respondents identified the support they received from MND charity organisations as helpful and *n* = 1 respondent recognised the support they received from being involved with wider MND professional and research networks.

- *'Feeling part of a wider group/network, including MNDA, UK MND Clinical Studies Group and TRICALS'* (Medical)
- *'The support from the MND association'* (Nurse)

**Organisational Supports: (*n* = 5)**
Organisational supports identified were in relation to having a supportive management structure, receptiveness to change, adequate funding for services and recognition of the time resourcing required to adequately care for individuals and families living with ALS/MND.

- *'Working in a setting that offers the opportunity to change things over the long term, is so very different from facing these shortcomings with no ability to do anything about it'* (Medical)
- *'Roles that are adequately funded to account for the additional time it takes to support the needs of people with MND'* (Dietitian)
- *'Supportive management and adequate funding' (Speech and Language Therapist)*

**Relationships and Communication with Patients and Families: (*n* = 7)**
Maintaining positive relationships and having opportunities for open communication with families was identified as helpful. This was identified as helpful in relation to graded provision of information, setting expectations and g*etting to know them* so that holistic and person-centred care could be provided.

- '*Maintain communication with patients to give them as much information and projection as possible'* (Nurse)
- '*Learn about their own lives and situations to take care of them'* (Physiotherapist)
- '*Family conference to reduce conflicts'* (Medical)

**Guidelines/Protocols: (n = 2)**
Two respondents identified that having protocols or guidelines to follow was helpful.
- ***'**Guidelines, collections of practical non-medical advice - on selecting, for example, additional equipment'* (Medical)
- *'Protocols to follow'* (Speech and Language Therapist)

**Intrinsic Professional Characteristics, Skills and Attributes:**
**Positive Reframing and Recognising Impact: (*n* = 11, 7%)**

Respondents found it valuable to reflect on and recognise the positive impact of the care they were able to provide. By focusing on what they *could* do, rather than what was beyond their control, professionals found meaning in their role and a sense of purpose in supporting individuals and families facing the challenges of MND.

- *'I cannot cure them but I can help with the day to day struggle concerning voice and speech'* (Speech and Language Therapist)
- *'Do my best professionally and accept that I can't control some things'* (Medical)
- *'Accepting that we are not able to 'save' anyone but that maintaining or improving QoL in some small way is enough. Forgiving myself, and those around me, for anything not done due to capacity issues. Not focusing on the past too much'* (Nurse)
- *'Remembering patients who died where I was able to help in some way'* (Medical)
- *'Focusing on what we have achieved'* (Nurse)
- '*Every day I work with ALS patients, even though there are tough days when you leave feeling down, I mostly feel that I help them a lot. I accompany them and help them face the various situations they go through in the best possible way'* (Medical)

**Experience: (*n* = 8)**

Respondents identified that having professional knowledge and experience of working with MND and other neurodegenerative diseases was a helpful factor for them.

- '*Having much experience in neurodegenerative diseases'* (Medical)
- '*Years of experience and education'* (Nurse)
- *'Gaining experience'* (Dietitian)

**Empathy: (*n* = 3)**

Respondents identified the importance of empathy as an attribute for professionals working with and interacting with individuals and families living with MND. One respondent also identified the importance of self-compassion in this context.

- *'To act and interact with empathy but not acting too sad on their behalf*' (Speech and Language Therapist)
- *'In my opinion, empathy is the most important thing towards patients and their relatives, but it is also very important to look after yourself'* (Physiotherapist)

**Humour:** (*n* = 4)

Respondents spoke about the use of humour both within their team/with colleagues and when working with patients and families, to lighten the anxiety or distress associated with the situations they were working with.

- *'When dealing with patients, humour is a quality that often comes in handy'* (Nurse)
- *'Managing to laugh even in difficult patient situations'* (Physiotherapy)
- *'I think we have a lot of dark humour in our service too, I'm not sure if that helps'* (Speech and Language Therapist)
- *'To share with them also funny moments during the week to wash out anxieties and reduce the burden'* (Medical)

**Perspective Taking: (*n*= 4)**
Four medics identified perspective-taking as a helpful strategy when working with individuals affected by MND. They described how acknowledging the challenges they themselves experienced was often accompanied by a deeper recognition of their own relative well-being. This contrast fostered a sense of gratitude and humility, as they reflected on how fortunate they were to have their health compared to the profound difficulties faced by the individuals and families in their care.

- *'I get to appreciate my own life more, when working with ALS patients who have everything to lose'* (Medical)
- *'Recalling that no matter how bad a situation or difficult I find a consultation, it is nothing compared with what the person living with ALS/MND is going through'* (Medical)
- *'My works helps to better understand the priority in the life'* (Medical)
- *'Reminding that (as of today) I do not have ALS'* (Medical)

**Mindfulness: (*n* = 4)**
Respondents identified the use of mindfulness strategies or practice during their working day as helpful.

- *'Mindfulness exercise during my working day'* (Psychologist)
- *'I recently completed a 6-week mindfulness course… that was very helpful'* (Speech and Language Therapist)
- 'Mindfulness at work has helped' (Nurse)

**Creativity (*n* = 1)**
**'**Being creative' (Occupational Therapist)

## Personal Supports:

**Self-Care and Life Beyond Work (n = 22)**
Respondents identified the importance of engaging in self-care, hobbies and leisure activities that gave them a clear focus outside of work. Respondents described a range of activities such as exercise, spending time in nature, music, reading and creative activities that helped them to unwind, reduce stress and create a positive work-life balance.

- *'I play sports in a club 2 or 3 times a week'* (Medical)
- *'I do good activities for myself in my free time, like running or walking in the nature'* (Physiotherapy)
- *'Creative outlets (I do a lot of craft e.g. dressmaking, lace making, embroidery etc)'* (Occupational Therapist)
- *'Invest time in personal life'* (Medical)
- *'Immersion in books and games as a wind down'* (Physiotherapist)
- *'Leisure activities help to reduce stress'* (Medical)
- *'Getting enough rest by exercising, spending time in nature'* (Social Work)
- *'Ensuring that I put good things in place outside of work that I enjoy*' (MND Care Coordinator)

**Family and Social Support Networks: (*n* = 12)**
In addition to collegial support, respondents identified the supportive role of their family, friends and social networks outside of the work environment.

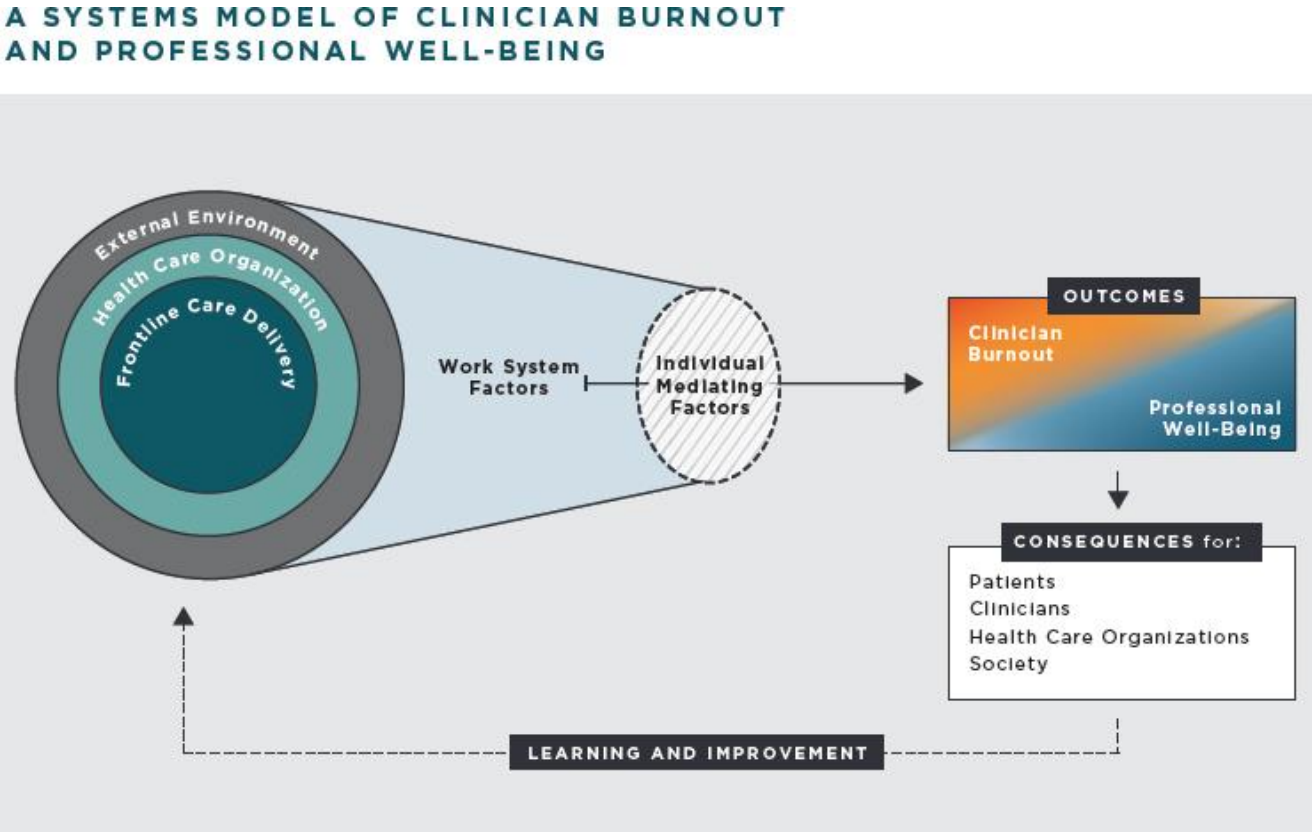
- '*Socialising with my family'* (Social Work)
- *'Friends/family just to talk things out with'* (Speech and Language Therapist)
- *'Seeing family/ friends'* (Physiotherapy)
- *'Support and communication with colleagues and family'* (Medica)
- '*Have time with my family'* (Medical)

**Religion/Faith/Spirituality: (*n* = 5)**
Religion, faith or spirituality was identified as an important supportive factor by 5 respondents.

- *'My faith'* (MND Care Coordinator)
- '*My Hindu beliefs'* (Medical)
- *'Being a Christian'* (Medical)

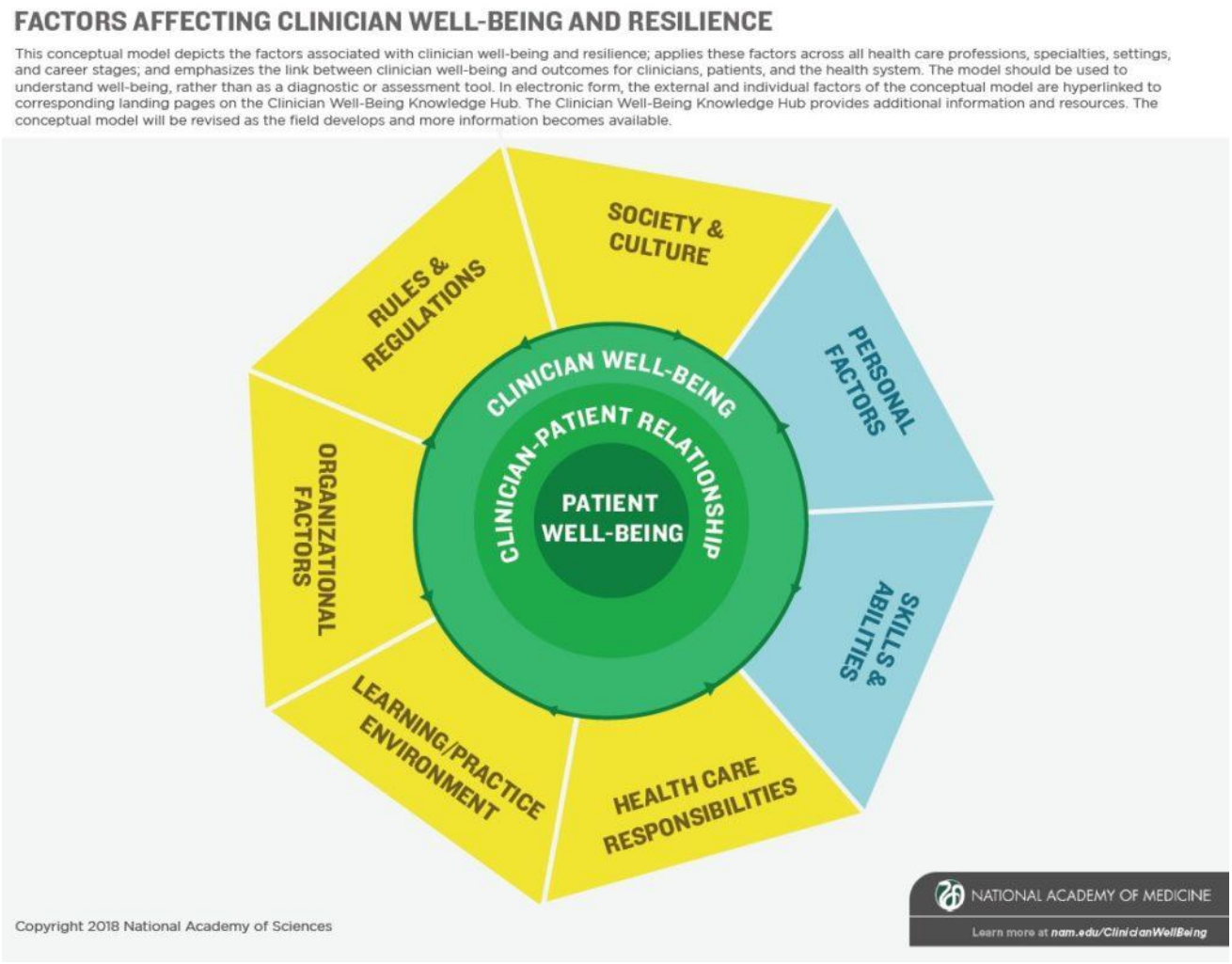
Responses provided by *n* = 168 respondents

**Appendix W:** Influential Models and Frameworks of Healthcare Professional Well-Being and Quality of Life



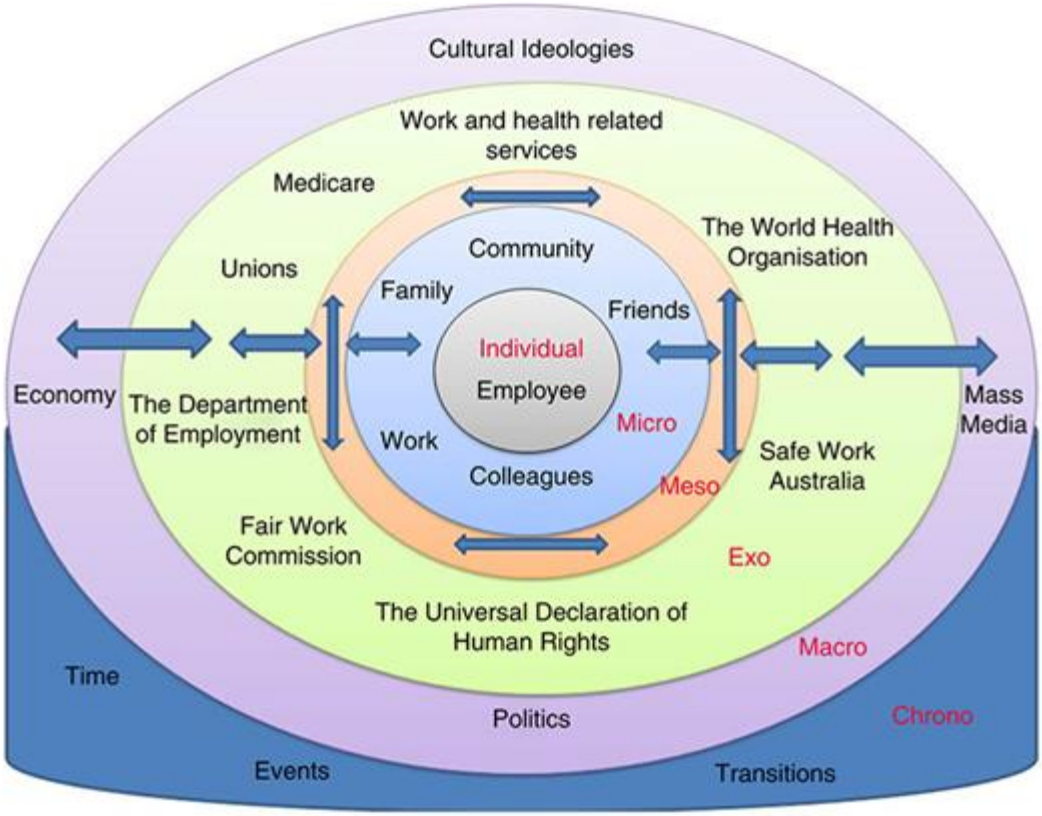

**Appendix W.1:** The Systems Model of Clinician Burnout and Professional Well-Being.

**National Academies of Sciences, Engineering, and Medicine (2019)** Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being. Washington, DC: The National Academies Press. https://doi.org/10.17226/2261.



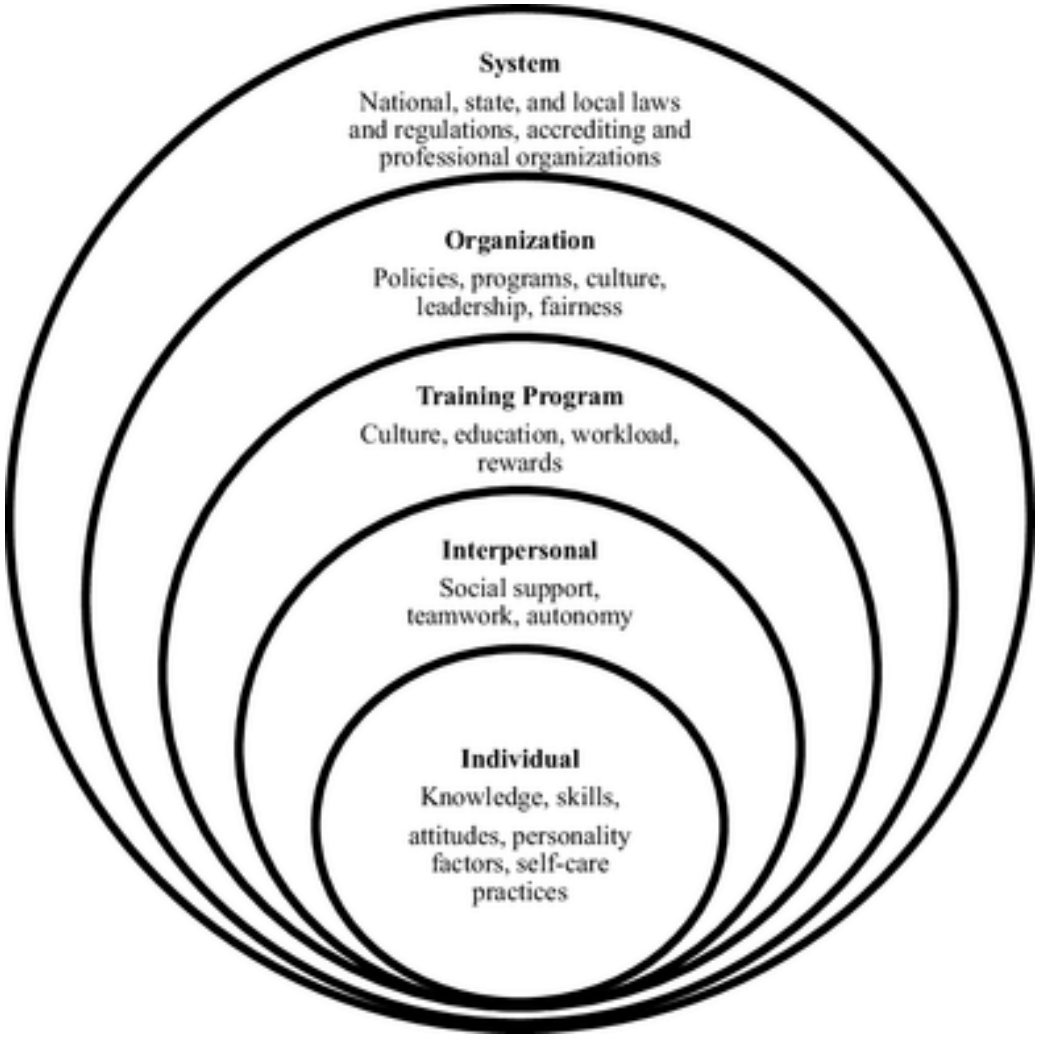

**Appendix W.2:** An All-Encompassing Conceptual Model of Factors Affecting Clinician Well-Being and Resilience

**Brigham, T., Barden, C., Dopp, A.L., Hengerer, A., Kaplan, J., Malone, B., Martin, C., McHugh, M. and Nora, L.M. (2018)** *A journey to construct an all-encompassing conceptual model of factors affecting clinician well-being and resilience*. *NAM Perspectives*: Discussion Paper, National Academy of Medicine. Available at: https://nam.edu/a-journey-to-construct-an-all-encompassing-conceptual-model-of-factors-affecting-clinician-well-being-and-resilience




**Appendix W.3:** The Bioecological Model of Workplace Health and Well-Being Management

**Bone, K.D. (2015)** 'The bioecological model: applications in holistic workplace well-being management', *International Journal of Workplace Health Management*, 8(4), pp. 256–271. doi: 10.1108/IJWHM-04-2014-0010.




**Appendix W.4:** *The Multilevel Model of Influences on Healthcare Professional Well-Being*

**Penwell-Waines, L., Ward, W., Kirkpatrick, H., Smith, P. and Abouljoud, M. (2018)** 'Perspectives on healthcare provider well-being: Looking back, moving forward', *Journal of Clinical Psychology in Medical Settings*, 25(3), pp. 295–304. doi: 10.1007/s10880-018-9541-3.

**Appendix X:** Extended Pillar Integration Process - Pillar Building Process Examples

## Example 1: System Level

| Data Source 1 (Scoping Review)<br><br>Descriptive Findings | Data Source 1 (Scoping Review)<br><br>Data substantiating the findings | Data Source 2 (Focus Group Study)<br><br>Descriptive Findings | Data Source 2 (Focus Group Study)<br><br>Data substantiating the findings | Data Source 3 (Online Survey)<br><br>Descriptive Findings | Data Source 3 (Online Survey)<br><br>Data substantiating the findings | Pillar Building<br><br>Iteratively developed themes |
|---|---|---|---|---|---|---|
| **Meta-theme: System Level** | | | | | | |
| Improved communication and information sharing between teams and services was identified as a key area for development.<br><br>Poor communication and collaboration between services was a source of | *The need for better communication and transfer of information between the teams and services involved was identified*. (Chapman, Bayes and Sim, 2021; Cipolletta and Reggiani, 2021)<br><br>*Managing the complex needs of motor neurone disease* | Feelings of significant isolation identified by primary care professionals providing care in the community, with perceived lack of collaboration with specialist and other services involved.<br><br>Specialist services could be limited in their ability to deliver services if community teams felt ill-equipped to manage MND | *"To get across that fragmentation and that like they just all the people that are involved and the number of healthcare professionals that can be involved and just I suppose that sense of isolation as a healthcare professional in the community working with somebody with MND" (SLT Primary Care)* | A majority had difficulty providing an intervention due to their reliance on an external service or provider.<br><br>A majority also witnessed compromised care for patients because of poor communication between professionals.<br><br>Open-text responses also highlighted the | Have difficulty providing an intervention due to reliance on another healthcare professional/organisation also involved in the person's care. (experienced by 53% of respondents)<br><br>Witness compromised care for individuals with ALS/MND because of poor communication between healthcare | **Service Integration and Care Coordination** |

| | | | | | | |
|---|---|---|---|---|---|---|
| significant frustration and often led to delays in care, duplicated efforts, and increased stress for professionals.<br><br>Individuals with limited exposure to the condition emphasised the importance access to specialists for comprehensive support, guidance, and education.<br><br>Specialist services are substantially reliant on community and local services to facilitate important | *patients and their families, required a large team and a union of authorities, teams and professionals. Co-ordinating the number of people involved was a frequently cited challenge.* (Olesen *et al.*, 2022)<br><br>*Professionals counteracting or duplicating each other's work was experienced when 'one side doesn't know what the other is doing'.*(McConigley *et al.*, 2014)<br><br>*Feelings of frustration and powerlessness were experienced by* | specific symptoms or care needs. They were also limited in their ability to implement important interventions when human resources or access to specific MDT members were constrained within the community.<br><br>There was a significant impact for patient care identified if there were delays in referrals and communication between services.<br><br>There was an identified need for greater awareness between services of each of their roles and remits.<br><br>There was also a recognised need for professionals to be willing to | *"After the equipment's in place is out of our control, then it's so dependent on the community OT and their community SLT and how well they're able to support and the availability they have". (SLT, ATSS)*<br><br>"I*f a referral comes in quite late to us and we're so cognisant of timing, funding and availability of equipment*" (OT ATSS)<br><br>*Remember that we're one part of the cog of the wheel and to look after somebody with MND that you have to be good at communicating with other healthcare* | impact of care coordination issues on the level of care that could be provided to patients and their families. | professionals. (Experienced by 58% of respondents)<br><br>*These were identified as the 11th and 12th highest stressors for professionals overall.*<br><br>Open-text Responses:<br><br>*"When challenged by other healthcare workers who you want to be involved but they don't prioritise the patient how you would".*<br><br>*"The chaotic nature of services meaning it's impossible to do as much as you want to do for people"* | |

| | | | | | | |
|---|---|---|---|---|---|---|
| aspects of patient care. | *professionals working with external teams who did not assign the same level of priority to motor neurone disease care, or refused to provide a service, due to the perceived level of complexity* (Gamskjaer, Werlauff and Handberg, 2022) | communicate and collaborate across various disciplines and services to provide effective MND care, given the complexity arising from multiple co-occurring symptoms, variability and changes in patient presentations. | *professionals about what your plan is" (*Nurse, Charity)<br><br>*"A lot of the issues that we see arise comes out from poor communication between teams, especially when if there's cognitive behaviour challenges and there's that manipulation between healthcare professionals and things like that, that it all comes down to communication at the end of the day"* (Nurse, Palliative Care) | | | |

## Example 2: The Interpersonal Level

| Data Source 1 (Scoping Review)<br><br>Descriptive Findings | Data Source 1 (Scoping Review)<br><br>Data substantiating the findings | Data Source 2 (Focus Group Study)<br><br>Descriptive Findings | Data Source 2 (Focus Group Study)<br><br>Data substantiating the findings | Data Source 3 (Online Survey)<br><br>Descriptive Findings | Data Source 3 (Online Survey)<br><br>Data substantiating the findings | Pillar Building<br><br>Iteratively developed themes |
|---|---|---|---|---|---|---|
| **Meta-theme: Interpersonal Level** | | | | | | |
| The importance of MDT working for effective care planning, delivery, and emotional support was identified.<br><br>In the absence of MDT support, professionals reported feeling overwhelmed, isolated, and vulnerable in their roles.<br><br>High levels of stress were reported when vacancies in key MDT roles, such | *The value of multidisciplinary team working, and strong professional relationships was discussed in twenty-one sources.*<br><br>*When professionals worked in what they perceived as a well-functioning multidisciplinary team, they felt enabled to deliver effective support and care for patients and their families* | The findings from the SR were corroborated in this study in relation to value and importance of MDT working and having all key members represented in MDT discussions about patient and family care planning and management.<br><br>Those working in inpatient settings often had better experiences of | '*Team support is vital it's not a role somebody can take on solo for sure' (Nurse, Charity)*<br><br>*'And so it's a real kind of MDT approach. I think. When you're supporting patients with MND.*<br>*It's kind of all hands on deck because it's, you know, it's often very stressful for trying to support these patients and their families' (MSW, Palliative Care)*<br><br>*I think that's what's really good is having the team around and* | A substantial percentage of respondents reported difficulty providing care because of poor communication within their team.<br><br>Working within a supportive multidisciplinary team environment was identified as the second most helpful support by respondents *n* = 63 (37.5%).<br><br>This category supported the idea | *58% of respondents experienced difficulty providing care because of poor communication between professionals or because of vacancies within a team.*<br><br>*These were ranked equally, at 11.5 out of 24, as the most frequently encountered barriers to providing effective MND care.* | **Working Within a Supportive Multidisciplinary Team** |

| | | | | | | |
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| as psychology, prevented the delivery of essential aspects of care. | *(Oliver and Turner, 2010; Musson et al., 2022; Olesen et al., 2022).*<br><br>*Effective teamworking was important for professionals and contributed to their job satisfaction (Gamskjaer, Werlauff and Handberg, 2022; Kloos, 2023)*<br><br>*Professionals also recognised the emotional support they received from working within a strong multidisciplinary model of care (Oliver, 2004; Mitsumoto and Rabkin, 2007; Cutler, 2009; Oliver and Turner, 2010;* | MDT approaches than those working in the community and those working in residential care settings had limited access to vital AHP support. | *being able to discuss at team meetings and just getting other team members experience as well and thinking right… you know, I'm not, I'm not experiencing this, I'm not experiencing this on my own. (Chaplain, Res Care)*<br><br>*'You're not taking on patients' issues in isolation, you're taking them on as a team'* (OT, MDT Clinic)<br><br>*'We also get a lot of support from each other, although it might not be hugely formal, there is a lot of support we get from eachother' (Nurse MDT Clinic)*<br>*I suppose the challenge is that we are lone workers, and we are going out by ourselves every day… we could be having very big* | that no one professional can take on the care of an individual living with MND alone, and that integrated and collaborative MDT working is required to both deliver effective care and support the healthcare professionals providing that care. This category included examples of teamwork for collaborative care planning, decision making, joint working and team learning or reflection.<br><br>The multidisciplinary nature of the work was also one of the factors that (*n*=21) professionals felt sustained them in | *Open- text responses:*<br><br>*MDT working with good communication' (MND Coordinator)*<br>*'Discussion with team/difficult cases/how to do better' (Nurse)*<br>*'When there are team meetings. discussions and support' (Occupational Therapist)*<br>*'Good teamwork with my colleagues, where we support each other in difficult situations'.(Medical)*<br>*'A supportive and positive team of colleagues working towards similar goals' (Nurse)*<br>*'Working as a team, having* | |

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| | *Hennessey, 2016)*<br><br>*In the absence of team support professionals reported feeling overwhelmed (Erlen, Burger and Tesone, 1990) vulnerable (Phelps et al., 2022) and isolated (Lerum, Solbraekke and Frich, 2017) when faced with making decisions or providing care alone.* | | *conversations with people …and maybe sometimes not having that… just when you're working in the hospital environment, you can maybe pop out of the room and have a chat with somebody…or there's somebody else that's just had that conversation with the same person*. (Nurse, Charity) | working with this population. | *medical and non-medical healthcare professionals around to talk about difficult cases and situations' (Meidcal)*<br>*'The collaboration between all professionals, that is essential' (Occupational Therapist)*<br><br>*'A good teamwork with my colleagues, where we support each other in difficult situations'.*<br><br>*'I am really happy with the team I work with, that outweighs the psychological strain of working with MND'* | |