Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

The mealtime experience of family carers of people with Motor Neurone Disease (MND)-related feeding and swallowing disabilities: A grounded theory study

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Thesis submitted to the School of Linguistics,
Speech and Communication Sciences
Trinity College Dublin

In fulfilment of the requirement of the Degree of Doctor of Philosophy

September 2024

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Summary

Family caregiving in Motor Neurone Disease (MND) can present a multitude of challenges to the physical and emotional health of family carers, owing to the palliative context of the illness and the unrelenting losses associated. Disability in feeding and swallowing is highly prevalent across the disease subtypes in MND, the nature and extent of which commonly necessitate family carer support. Family carers not only ensure care-recipients meet nutrition and hydration needs necessary for sustaining life, but their role extends far beyond this to the management of complex psycho-emotional and psycho-social aspects of feeding and swallowing disability.

Existing research has focused on the physiological consequences of impairment when investigating swallowing disability in MND, while broader consequences of feeding and swallowing disability, those within the psycho-social domain, have been under-researched. This study advances the evidence base on the psycho-social impact of feeding and swallowing disability in MND by focusing on the third-party impact of this disability. Understanding the extent of impact of this disability from the perspective of family carers is paramount, given that best practice in palliative care urges care that is family-centred.

This study utilised a qualitative approach with grounded theory methodology to address the research aim, which was to develop an in-depth understanding of the mealtime experience from the perspective of family carers of people with MND (PwMND). The generation of a conceptual framework to account for family carer experience and guide future research, practice and policy was the anticipated end-product of the study.

The study took place in the Republic of Ireland (ROI) where 21 family carers participated. Participants were recruited with assistance from gatekeepers within the Trinity College, Dublin (TCD)-based Research Motor Neurone (RMN) group, the National Centre of ALS/MND at Beaumont Hospital (Dublin), and the Irish Motor Neurone Disease Association (IMNDA). In-depth, semi-structured interviews were the primary method of data collection. Interviews were conducted with individual family carers regarding their experience of MND-associated feeding, swallowing and mealtime changes. In keeping with grounded theory methodology, interview schedules evolved over the data set in response to theoretical leads which arose through concurrent data collection and analysis. Data analysis involved open, axial, and selective coding of interview transcriptions. NVivo software was used to facilitate data management. Reflexive memos, theoretical memos,

and concept diagramming informed theoretical sampling which was necessary to achieve the conceptual framework.

This study identified the emotional landscape underpinning participant experience as one characterised by sadness and loss, fearfulness, anger and frustration, guilt and regret. Negative psycho-emotional sequalae arose early in the experience of disability and were magnified by illness unpredictability and uncertainty. Family carers' lack of control over the progression of feeding, swallowing and mealtime-related consequences further magnified negative psycho-emotional outcomes. Feeding, swallowing and mealtime changes required bearing, braving and persevering as family carers felt they were living the illness with the PwMND. The actions of health and social care professionals (HSCPs) could alleviate or induce negative psycho-emotional sequalae. HSCPs influence on family carer hope was particularly salient for family carers.

Protection was uncovered as the central concept framing family carer action and interaction as they provided care to PwMND who experienced feeding, swallowing and mealtime challenges. Protection not only applied to the PwMND but to the wider family unit and family carers themselves. Family carers, in their dual role as family members and care providers, orientated protection to physical, psycho-emotional, and/or psycho-social functioning. Prioritisation of family carer protection was dependent on care-recipient, wider family unit and family carer-related factors. The pre-existing nature of the relationship between care-recipients and family carers was integral to family carers' ability to navigate changes in the relationship dynamic. These changes were unavoidable particularly when dependency for feeding and swallowing arose.

Key operational strategies family carers used to enact protection in the context of feeding, swallowing and mealtime changes were identified in this study. These strategies included problem solving, balance and compromise, gatekeeping, strategic communication, change management, teamwork and leadership. Such strategies often occurred concurrently, and required care-recipient, wider family unit and HSCP support to optimise effectiveness. Operational strategies used by family carers arose via overt or covert surveillance and judgement of eating, drinking and mealtime situations, with the desire to remain watchful being ever present for family carers.

This study provides a novel understanding of the depth of disruption that feeding, swallowing and mealtime difficulties present for family carers. The findings illustrate the extent of the contribution family carers make to the care of PwMND. Knowledge arising from this study can inform healthcare providers and enhance support for the wellbeing of these essential partners in care.

Acknowledgements

I would sincerely like to thank the team of people I have had supporting me, who willed me on at every step of this study and in completing this thesis.

Firstly, I would like to thank the Department of Clinical Speech and Language Studies for supporting me in this endeavour. You have provided a wonderful academic home for me over the last decade. Thank you for awarding me the studentship that enabled me to pursue this research and for educating and training me so that I could make this contribution.

Thank you to Dr. Margaret Walshe for first accepting my application to the Postgraduate Diploma programme and for later inspiring me to pursue Masters-level studies. You have always been a source of momentum for improving the profession in Ireland, and I have been so lucky to benefit from your guidance.

To Dr. Geraldine Foley, the co-supervisor for this PhD, whom I was extremely fortunate to have had as a supervisor. I have benefitted immeasurably from your input in so many ways. You have shared with me your wealth of knowledge and experience in Motor Neurone Disease, your expertise in qualitative methodology (and in particular grounded theory), and your mastery of academic writing. Your drive, determination and dedication to research are inspiring. I am deeply thankful for your advice, input, guidance, and the comprehensiveness of your feedback at all stages of this process.

To Dr. Caroline Jagoe, the primary supervisor for this PhD. Thank you for seeing the potential in this research and in me. Thank you for supporting every aspect of this project, from securing the initial funding to seeing it through to completion. Thank you for your graceful navigation of the ups and downs which formed my PhD journey and for the generous investment of your time and effort, despite the high demands of your many roles. Thank you for the numerous opportunities, the flexibility, responsiveness, and generosity in sharing your extensive knowledge. Your unremitting encouragement kept me going in this process, and I am incredibly grateful for the privilege it has been to be mentored by you.

I would like to extend my gratitude to all at Research Motor Neurone, the National Specialist Centre for ALS/MND in Beaumont Hospital (Dublin), and the Irish Motor Neurone Disease Association for supporting this project. Thank you, in particular, to Prof. Orla Hardiman, Mr. Mark Heverin, and Mr. Colm Peelo for your commitment to facilitating the ethical approval, gatekeeping and recruitment processes which were instrumental in

this study. Your dedication to people affected by Motor Neurone Disease is nothing short of exceptional.

A very big thank you to my colleagues at St. James's and St. Luke's Hospital, Dublin. Your support and encouragement have meant the world to me. A special thank you to Ms. Gina O'Donohue and Ms. Deirdre Gilchriest, Speech and Language Therapy Managers at St. James's Hospital, for your encouragement throughout this process. Thank you also for the opportunity you gave me to divert from clinical work in order to complete this thesis.

On a personal note, I'd like to thank my friends and family, especially the ones who work in areas outside of health. You have kept me motivated throughout this project with your relentless backing. Thank you for the copious amounts of accommodations you have made for me, for your inspiration, and for keeping me laughing.

To my Mum, Jan Rigoll, who has made countless sacrifices for me from the very beginning. Thank you for teaching me to work hard, never give up, and to do what I can to help others. Thank you for encouraging me to take this opportunity and for your unwavering belief in me.

To my sweet little creatures, Elise, Adrian, and Jude. If I had to magic up three helpers, they wouldn't come anywhere close to how helpful you guys have been. Each one of you has been amazing -Elisey from the very beginning, and Adrian and Jude jumping on board in the middle. Thank you for having all the confidence in me and for your endless encouragement (and treats).

To Dec. There's not enough space on the paper. Thank you for seeing the value in this endeavour and for supporting me no matter what. You have been as solid as a rock. Thank you for creating space in your life for my PhD, and for all that came with it. I am incredibly grateful for your listening, motivation, strategic management skills, and your constant supply of beverages. From the bottom of my heart, thank you.

Finally, I extend my deepest appreciation to the participants of this study. You taught me so much more than I could ever convey on these pages. I continue to be deeply humbled by the openness and honesty that you showed me throughout our interviews. Thank you for opening your homes to me as another unfamiliar face, and for your patience, trust, and kindness. Your bravery and selflessness will not be forgotten, and they will be held alongside your words, stories, and advice. I sincerely hope I have honoured your investment in this process with something that can be used to help the family carers who will come after you.

This thesis is dedicated to my family

Table of Contents

LIST OF TABLES.....xiv

LIST OF FIGURES.....xv

LIST OF ABBREVIATIONS.....xv

DEFINITION OF TERMS.....xvi

SECTION ONE: Introduction and literature review.....1

Chapter 1: Introduction.....2

1.1 Introduction.....2
1.2 Orientation to the current study.....3
1.3 Aims and objectives.....5
1.4 Researcher positionality.....6
1.5 Thesis structure.....7

Chapter 2: Literature review.....10

2.1 Introduction.....10
2.2 Motor Neurone Disease: An overview.....11
2.2.1 Classification.....12
2.2.2 Diagnosis.....14
2.2.3 Prognosis and prognostic indicators.....14
2.2.4 Tenets of management.....15
2.2.4.1 Multidisciplinary care.....16
2.2.4.2 Integration of health services.....18
2.2.4.3 Quality of life.....19
2.2.4.4 Family-centred care.....20
2.3 Family caregiving in Ireland.....21
2.3.1 The value of family carers.....22
2.3.2 Negative outcomes experienced by family carers of people with MND.....23
2.3.3 Reciprocity of family care in MND.....24
2.4 Feeding and swallowing impairment in MND.....25
2.4.1 Using the International Classification of Functioning, Disability and Health Framework (WHO, 2001) to conceptualise feeding and swallowing disability in MND.....26
2.4.2 Oropharyngeal dysphagia in MND: The nature of the swallowing impairment and the impact on body structure and function.....27
2.4.3 Oropharyngeal dysphagia in MND: Impact on activity and participation.....30
2.4.4 Oropharyngeal dysphagia in MND: Considering contextual factors which contribute to the experience of disability.....33
2.4.4.1 Personal factors.....33
2.4.4.2 Environmental factors.....35
2.4.5 Management of oropharyngeal dysphagia: The context of healthcare professionals.....38
2.5 Family carers and the extent of third-party disability in feeding and swallowing impairment.....40
2.6 Theoretical context of the current study.....41
2.6.1 Grounded theory as an opportunity to build an evidence base.....42
2.7 Conclusion.....44

SECTION TWO: Research methodology and methods……..46

Chapter 3: Research methodology and methods……47

3.1 Introduction……47
3.2 Research methodology……47
3.2.1 Rationale for using qualitative methodology……47
3.2.2 Research paradigm: Critical realism……48
3.2.3 Axiology of critical realism……50
3.3 Research approach……52
3.3.1 Considering research designs ……52
3.3.2 Grounded theory as a family of methods……53
3.3.3 Evolution of grounded theory……54
3.3.4 Contrasting Classical, 'Corbin and Strauss', and Constructivist grounded theory….54
3.3.4.1 Research end-product in grounded theory……58
3.3.5 Rationale for 'Corbin and Strauss' grounded theory……59
3.4 'Corbin and Strauss' grounded theory: Methodological procedures……60
3.5 The role of the researcher……61
3.6 Research methods……62
3.6.1 Ethical approval……62
3.6.2 Ethical considerations……63
3.6.2.1 The voice of the family carer……63
3.6.2.2 Protection of research participants: Informed consent……64
3.6.2.3 Protection of research participants: Beneficence and non-maleficence……65
3.6.2.4 Protection of research participants: Confidentiality and anonymity……66
3.7 Participant recruitment……67
3.7.1 Initial sampling……67
3.7.2 Access to participants……68
3.7.3 Participant selection……69
3.7.4 Recruitment activity……70
3.7.5 Sample size……72
3.7.6 Interviews……72
3.7.7 Sample characteristics……73
3.8 Data collection……80
3.8.1 Interviewing……80
3.9 Data recording……81
3.9.1 Audio-recording equipment……81
3.9.2 Observational field notes……81
3.9.3 Reflexive journal……82
3.10 Preparation of data for analysis……82
3.10.1 Transcription of interviews……82
3.10.2 Memoing……83
3.11 Data analysis……83
3.11.1 Open coding……84
3.11.2 Axial coding……85
3.11.3 Selective coding……87
3.11.3.1 Theoretical sensitivity……88
3.12 Ensuring research quality……89
3.13 Conclusion……89

SECTION THREE: Research findings……93

OVERVIEW OF RESEARCH FINDINGS……94

Chapter 4: Bearing, braving and persevering: The context of feeding, swallowing and mealtime challenges for family carers……98

4.1 Introduction: Living the illness with the person you are feeding……98
4.2 Facing downwards but not giving up: Supporting feeding, swallowing and mealtime disability in the context of palliative illness……100
4.2.1 Subsuming sadness and ongoing loss……100
4.2.2 Fearfulness: From apprehension to terror……106
4.2.3 Encountering anger and frustration……109
4.2.3.1 Anger, frustration and the family carer – healthcare professional interface……112
4.2.4 Mitigating current and future guilt, and avoiding regret……114
4.2.5 Maintaining hope……117
4.3 Unpredictability, uncertainty and a lack of control……121
4.3.1 Illness unpredictability……121
4.3.2 Reduced sense of control……124
4.3.3 Uncertainty, with the exception of death……125
4.4 Remaining present in the moment to maintain hope……127
4.4.1 Living in the moment……127
4.4.2 Learning in the moment……129
4.5 Conclusion……130

Chapter 5: Core category- *Protecting*: The essential element framing the feeding, swallowing and mealtime experiences of family carers ……131

5.1 Introduction……131
5.2 Protecting the health status of the care-recipient……133
5.2.1 Protecting the physical status of the care-recipient……134
5.2.1.1 Protecting care-recipient nutritional status……134
5.2.1.2 Protecting the care-recipient from choking……136
5.2.1.3 Protecting safety in advanced illness……137
5.2.2 Protecting the psycho-emotional status of the care-recipient ……139
5.2.2.1 Protecting the care-recipient from embarrassment and shame……140
5.2.2.2 Protecting the care-recipient from isolation and frustration……143
5.2.2.3 Protecting the care-recipient from fear……143
5.2.3 Protecting care-recipient dignity……144
5.2.3.1 Protecting independence and autonomy……144
5.2.3.2 Protecting independence and the interface with formal care providers……145
5.2.3.3 Protecting care-recipient control and choice……147
5.2.3.4 Infantilising as a specific threat to dignity……148
5.2.4 Protecting care-recipient quality of life……149
5.2.4.1 Care-recipient quality of life, and the role of food and drink-related routines and rituals……150
5.3 Protecting the wider family unit: Maintaining social equilibrium……152
5.4 *Protecting* orientated towards the health status of self……158
5.4.1 Protecting the physical status of self……159
5.4.2 Protecting the psycho-emotional status of self……161
5.4.3 Protecting the pre-existing relationship between the members of the care dyad…162
5.4.3.1 Relationship quality as a factor influencing the ability to withstand relationship challenges in feeding, swallowing and mealtime disability……163
5.4.3.2 The nature of the relationship as a factor influencing the family carer's ability to protect the relationship from challenges in feeding, swallowing and mealtime disability……166

5.4.3.3 Shared challenges as a protective factor in relationship changes within the care dyad……168
5.4.3.4 Reinforcing interpersonal connection through care dyad-shared food and drink routines and rituals……169
5.5 Conclusion……169

Chapter 6: Watchful shepherding: The operationalisation of *protecting* ……171

6.1 Introduction……171
6.2 Surveillance and judgement of feeding and swallowing situations……172
6.2.1 Problem solving: Building on skill set and seeking out expertise……173
6.2.2 Balance and compromise……178
6.2.3 Gatekeeping……182
6.2.4 Communicating strategically……186
6.2.4.1 Change management and the role of health and social care professionals……191
6.2.5 Teamwork and "taking the lead"……193
6.3 Conclusion……195

SECTION FOUR: Discussion of research findings……197

Chapter 7: Synthesis of findings……198

7.1 Introduction……198
7.2 Discussion of findings……198
7.2.1 Onset of feeding and swallowing impairments is transformative for family carers.198
7.2.2 The unique psycho-emotional landscape associated with feeding and swallowing impairment in MND……200
7.2.3 The unique psycho-social landscape associated with feeding and swallowing impairment in MND……204
7.2.3.1 Stigmatisation associated with feeding, swallowing and mealtime difficulties amongst care dyad members……204
7.2.3.2 Normalcy and the personal meaning of food and drinks within the care dyad...207
7.2.3.3 Identity and the family carer in the context of the mealtime……208
7.2.3.4 Relationship changes between the person with MND and the family carer: Parentification, infantilisation and separation……209
7.2.4 Facilitators of, and barriers to, family carers in supporting the person with MND with feeding and swallowing difficulty……210
7.2.5 Coping for family carers as enabled through *remaining present in the moment*….212
7.2.6 The centrality of hope for family carers……213
7.3 Conclusion……213

Chapter 8: Clinical implications of the study findings……214

8.1 Introduction……214
8.2 Implications of the findings for speech and language therapy services……215
8.2.1 Emphasis on a family-centred approach from the initiation of care……215
8.2.2 Commencement of speech and language therapy intervention in response to family carer and care-recipient perceived need……216
8.2.3 Choice in speech and language therapy service delivery for family carers……217
8.2.4 Flexibility in speech and language therapy intervention schedules……217
8.2.5 Direct family carer access to speech and language therapy services……218
8.3 Optimising the therapeutic relationship between the family carer and health and social care professionals……219

8.3.1 Embodying therapeutic qualities which enhance family carer engagement……219
8.3.2 Acknowledging the burden of care……..…..220
8.3.3 Acknowledging family carers as experts through their experience of caring for the person with MND……..……221
8.3.4 Limiting threats to family carer hope in the clinical interaction……...221
8.4 Sensitively orientating the role of the speech and language therapist……...…222
8.4.1 Translating knowledge of the psycho-social consequences of feeding, swallowing and mealtime impairment into practice……..…222
8.4.2 Providing care responsive to the coping and adaptation style of family carers……224
8.4.2.1 Goal setting……..……..…224
8.4.2.2 Sharing information with family carers……225
8.5 Indications for specific interventions within the scope of speech and language therapy practice……...226
8.5.1 Choking management……..……..226
8.5.2 Gastrostomy feeding……..……..…228
8.5.3 Eating and drinking 'at risk' ……..……229
8.6 Implications for service planning: Organisational level……..……230
8.6.1 The need for speech and language therapy services in palliative care contexts….230
8.6.2 Access to psychology and social work services for family carers in MND……...231
8.6.3 The provision of case managers for the coordination of care……..……232
8.6.4 Improved access to and availability of state-funded home help and respite services……...233
8.7 Conclusion……..……..……..……..…234

Chapter 9: Implications for future research……..……..……236

9.1 Introduction……236
9.2 Focusing the research to support evidence-based care……..…236
9.2.1 Indications for further family carer-based research concerning feeding, swallowing and mealtime experiences in MND……..……237
9.2.1.1 Considering study design and procedures……..……237
9.2.1.2 Considering participant characteristics……..…...239
9.2.1.3 Considering design and delivery of MND care services……...…241
9.2.2 Indications for speech and language therapist-centred research……243
9.2.3 Considering broader research implications……..…246
9.3 Conclusion……..247

SECTION FIVE: Conclusion……248

Chapter 10: Conclusion……249

10.1 Introduction……249
10.2 Strengths and contributions……249
10.3 Challenges and limitations……....251
10.4 Consideration of study procedures……252
10.5 Summary of contribution to knowledge ……257
10.6 Concluding remarks……....259

REFERENCES……..……263

APPENDIX 'A' CONDITIONAL/CONSEQUENTIAL MATRIX (CORBIN & STRAUSS, 2008/2015)……..319

APPENDIX 'B' CONSENT FORM……..……..320

APPENDIX ‘C’ PARTICIPANT INFORMATION SUMMARY……323
APPENDIX ‘D’ POSTER……324
APPENDIX ‘E’ PARTICIPANT INFORMATION LEAFLET……325
APPENDIX ‘F’ INITIAL INTERVIEW GUIDE……...328
APPENDIX ‘G’ REFLEXIVE JOURNAL EXCERPT ……..……...330
APPENDIX ‘H’ TRANSCRIPTION CONVENTIONS……..…...331
APPENDIX ‘I’ METHODOLOGICAL MEMO EXCERPT……332
APPENDIX ‘J’ THEORETICAL MEMO EXCERPT……334
APPENDIX ‘K’ TRANSCRIPTION “TONY”……...337
APPENDIX ‘L’ ILLUSTRATION OF CORBIN & STRAUSS (2008) CODING PROCESS……353
APPENDIX ‘M’ CRITERIA FOR EVALUATING THE QUALITY OF GROUNDED THEORY STUDIES (CORBIN & STRAUSS, 2015)……356
APPENDIX ‘N’ ADAPTED INTERVIEW GUIDE……358
APPENDIX ‘O’ DATA DRIVEN ACTION/INTERACTION INFLUENCING CONDITIONS MAPPED USING THE CONDITIONAL/CONSEQUENTIAL MATRIX (CORBIN & STRAUSS, 2008/2015)……360
APPENDIX ‘P’ SPEECH AND LANGUAGE THERAPY CLINICAL CONSIDERATIONS ARISING FROM THE DATA……361

List of Tables

Table 1. Sub-types of MND……13

Table 2. Framework for MND care (Hardiman et al., 2002).…….....18

Table 3. Oropharyngeal dysphagia management options reported in the literature (Waito et al., 2017)……..……40

Table 4. Relevant theoretical context situating the current study……43

Table 5. Main approaches to grounded theory (Breckenridge et al., 2012; Charmaz, 2008; Evans, 2013; Kenny & Fourie, 2015; Skeat & Perry, 2008)……..55

Table 6. Ethical approval processes……64

Table 7. Inclusion/Exclusion criteria……..……..70

Table 8. Recruitment activity……..71

Table 9. Reasons for declining participation after gatekeeper identification……..71

Table 10. Interview characteristics……...73

Table 11. Collated participant characteristics……74

Table 12. Individual participant characteristics……..……..76

Table 13. Care-recipient characteristics……79

Table 14. Stages of coding (Corbin & Strauss, 2008) ……..….84

Table 15. Strategies to maximise research quality (Corbin & Strauss, 2015; Lincoln & Guba, 1985/2005)……..…….91

List of Figures

Figure 1. Map showing participation by province of residence at the time of interview……..……...75

Figure 2. The conceptual framework representing the feeding, swallowing and mealtime experiences of family carers of people with MND……..94

Figure 3. The psycho-emotional context of family carers of people with MND-induced feeding, swallowing and mealtime difficulty……..99

Figure 4. The core category *protecting* applied to the family carer experience of feeding, swallowing and mealtime challenges in MND……132

Figure 5. Key actions and interactions underpinning family carer operationalisation of care in the context of feeding, swallowing and mealtime challenges in MND……172

List of Abbreviations

AIIHPC	All Ireland Institute of Hospice and Palliative Care
ALS	Amyotrophic Lateral Sclerosis
EoL	End of life
FTD	Frontotemporal Dementia
GP	General Practitioner
GT	Grounded theory
HCP	Healthcare Professional/s
HIQA	Health Information and Quality Authority
HSCP	Health and Social Care Professional/s
HSE	(Irish) Health Service Executive
IASLT	Irish Association of Speech and Language Therapists
ICD-11	International Statistical Classification of Diseases and Related Health Problems (Revision 11)
ICF	International Classification of Functioning, Disability and Health Framework
IMNDA	Irish Motor Neurone Disease Association
LMN	Lower Motor Neurone
MDT	Multidisciplinary team
MND	Motor Neurone Disease
MND NZ	Motor Neurone Disease New Zealand
MREC	Medical Research Ethics Committee
MRI	Magnetic Resonance Imaging
NCPPC	National Clinical Programme for Palliative Care
NG	Nasogastric tube
NICE	National Institute for Health and Care Excellence
NPO	Nil Per Os (nil per oral)

PBP	Progressive Bulbar Palsy
PEG	Percutaneous Endoscopic Gastrostomy
PLS	Primary Lateral Sclerosis
PMA	Progressive Muscular Atrophy
PPI	Public and patient involvement
PwMND	Person/People with Motor Neurone Disease
QoL	Quality of life
RCSLT	Royal College of Speech and Language Therapists
REC	Research Ethics Committee
RIG	Radiologically Inserted Gastrostomy
RMN	Research Motor Neurone
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus-2
SLT	Speech and Language Therapist/Therapy
SWAL-QOL	Swallowing Quality of Life Questionnaire
TCD	Trinity College Dublin
UK	United Kingdom
UMN	Upper Motor Neurone
WHO	World Health Organisation

Definition of Terms

Aspiration	Entry of material (e.g., food, fluids, secretions) into the airway, below the level of the true vocal folds
Aspiration pneumonia	Respiratory infection associated with the entry of non-air substances (e.g., food, fluids, stomach contents, saliva) into the airway
Care dyad	The dyad formed between the family carer and the care-recipient
Care triad	The triad formed between the family carer, care-recipient and professional healthcare providers
Dimensional continuum	Developed during open coding by scrutinising properties pertaining to a category (e.g., frequency/ intensity/duration) in order to establish the dimensional range of that category (Strauss & Corbin, 1990)
Dysarthria	Disorder of speech
Eating and drinking 'at risk'	Term used to refer to continued eating and drinking with acknowledgement of the risks associated with dysphagia
Electromyography	A diagnostic procedure to assess the health of muscles and the nerve cells that control them (motor neurones)
Enteral feeding	Feeding directly into the gastrointestinal tract using a feeding tube
Family carer	An individual who provides assistance to a family member with some level of dependence for care
Forced vital capacity	The vital capacity of the lungs determined from a maximally forced expiration
Formal health/care	Professional health/care service
Frontotemporal dementia	A fatal neurodegenerative disease, characterised by frontotemporal brain atrophy, with mainly cognitive and behavioural symptoms (Neary et al., 2005)
Gastrostomy feeding	Feeding via a tube inserted directly into the stomach which enables nutrition, hydration, and medications to be delivered
Health Service Executive	The publicly funded healthcare system in Ireland
IMNDA	Voluntary support organisation in Ireland providing care for people with Motor Neurone Disease, their families, friends and carers

Informal health/care	Non-professional health/care supports
Laryngeal penetration	Entry of materials into the airway, but not below the level of the true vocal cords
Milford Care Centre	A palliative care centre in Limerick providing inpatient, domiciliary and day care supports
Nerve conduction studies	Part of an electromyography assessment, which uses surface electrodes to measure the speed and strength of signals travelling between two or more points on a nerve
Oropharyngeal dysphagia	A disorder of swallowing which interferes with the ability to safely and efficiently move food and fluids from the mouth, through the pharynx and into the oesophagus (Logemann, 1998)
Paradigm model	A structure for coding data which involves consideration of causal conditions, context, intervening conditions, action/interactional strategies, and consequences to connect categories. Used during axial coding (Strauss & Corbin, 1990)
Research Motor Neurone Ireland	A research institute investigating Motor Neurone Disease which is based at Trinity College Dublin
Sialorrhoea	Excessive drooling
Theoretical saturation	The point at which gathering more data about theoretical categories reveals no new properties or any further theoretical insights about the emerging grounded theory. At this point, the dimensional variation of categories has been well developed (Corbin & Strauss, 2015)
Third-party disability	Disability of a family member which is experienced due to the health condition of a significant other (WHO, 2001)

SECTION ONE

INTRODUCTION AND LITERATURE REVIEW

Chapter One

Introduction

1.1 Introduction

Eating and drinking, together with the routines and rituals associated with eating and drinking, fulfil not only basic biological functions but important social functions. Planning, preparing, and participating in food, drink, and mealtime-related activities is known to be interconnected with an individual's sense of identity and culture (Aktaş-Polat & Polat, 2020; Méndez-Montoya, 2012). Disruption of biological and social functioning can occur for individuals with illnesses affecting the ability to eat, drink, and participate in mealtimes. Motor Neurone Disease is one illness in which disorders of self-feeding, eating, and drinking can have vast implications extending beyond the individual with the illness, to impact members of the wider family unit.

The term Motor Neurone Disease (MND) is a hypernym which refers to a group of neurodegenerative disorders of sudden onset and rapid progression; a profile of complex disabilities and fatal consequences resulting from the degeneration of motor neurones in the brainstem, spinal cord, and corticospinal tracts (Aoun et al., 2013; McLeod & Clarke, 2007; Murphy, 2004; Paris et al., 2013). The names MND and Amyotrophic Lateral Sclerosis (ALS) are often used interchangeably (Aoun et al., 2012; Whitehead et al., 2012). In Ireland and the United Kingdom (UK), MND is the term most commonly used to encapsulate this group of illnesses. The median age of onset of MND in Ireland is 67 years of age (McFarlane et al., 2023). Although relatively rare, MND is the third most frequent neurodegenerative disease after Alzheimer's disease and Parkinson's disease (Talbot, 2014). The rate of incidence for MND is higher in Ireland than in many European countries (Chiò et al., 2013). Currently, there are 380 people living with MND in Ireland, and approximately 150 new diagnoses are made each year (Hardiman et al., 2021). Global numbers of MND are increasing, with a 69% rise in global incidence predicted by 2040 (Arthur et al., 2016).

MND is a terminal disorder of the central nervous system (Hardiman et al., 2011), which can progress to an incomplete locked-in state in which individuals are unable to move or communicate by verbal means (Kübler et al., 2005; Lulé et al., 2009). Targeted curative treatments of the disease mechanism in MND are not currently available (Corcia & Gordon, 2012). Treatment aims to slow down the progression of the illness, optimise symptom management and enhance quality of life (QoL) (Miller et al., 2012). A palliative

care approach, outlined by the World Health Organisation (WHO) (Sepúlveda et al., 2002) as encompassing the physical, emotional, social, and spiritual aspects of the disease is recommended from the time of diagnosis (Bede et al., 2011). Palliation, occurring alongside active treatment aimed at prolonging life, continues through care at the end of life (EoL) and extends into the bereavement period for family members affected by illness presence within the family unit.

Often the preference of people with MND (PwMND) is to remain at home throughout their illness course (Galvin et al., 2020). Reliance on family members and friends is typically unavoidable as progressive functional decline impacts the individual's independence for self-management (Galvin et al., 2020). The extent of care demands means that family carers often become critical members of the care team, addressing numerous and often complex needs, enabling the PwMND to continue to remain at home during the illness course (de Wit et al., 2018; Galvin et al., 2020). Family carers within the general population are known to experience negative consequences related to their undertaking of caregiving roles (McGarrigle & Kenny, 2020). Family carers who support PwMND are particularly prone to high levels of burden, and vast psycho-emotional and psycho-social consequences, which can significantly alter their QoL (Cipolletta & Amicucci, 2015; de Wit et al., 2018).

1.2 Orientation to the current study

Extensive profiles of disability resulting from MND implicate the involvement of informal caregivers together with a comprehensive array of multidisciplinary healthcare professionals (HCPs) to optimise outcomes for the individuals directly impacted by this illness (Talbot et al., 2018). Given that family-centred care is emphasised in Irish palliative healthcare models (National Clinical Programme for Palliative Care [NCPPC], 2019), health and social care professionals (HSCPs) are compelled to consider outcomes for members of the supporting family unit throughout the duration of their healthcare interventions.

MND-related self-feeding, swallowing and mealtime changes are one important focus in disease management for both PwMND (Lisiecka et al., 2021) and their family carers (Lisiecka et al., 2020). Family carer responsibility to support the nutrition, hydration, and social needs of care-recipients relative to self-feeding, eating, and drinking difficulties increases with increased disease-related functional decline in MND (Lisiecka et al., 2020). The effect of feeding, swallowing and mealtime changes on PwMND and their family members is not yet well understood. This thesis pursues the opportunity to enhance

family-centred management of feeding and swallowing disability for PwMND. Extending the evidence base by describing and explaining the impact of feeding and swallowing impairment for families impacted by MND was paramount in this study.

The conceptualisation of the study reported in this thesis is aligned with an “intense interest in understanding and analysing how dying, pain, chronic illness, and illness in general are perceived and handled by staff members, relatives, and patients, how they become an object of work and require sophisticated organisation of work” (Riemann & Schütze, 1991, p. 333). Current understanding of the experience of oropharyngeal dysphagia in MND from the perspectives of PwMND, their relatives, and HCPs is incomplete. This is consistent with the dearth of information available across the wider cohort of people impacted by oropharyngeal dysphagia. In progressive neurological illness, the informal care dyad, that is, the person directly impacted by the illness together with their supporting family member, has been underserved in dysphagia research. Studies aiming to illuminate the psycho-social challenges of feeding and swallowing impairment are particularly scarce.

Multidisciplinary healthcare teams, involving speech and language therapists (SLTs), occupational therapists, clinical nutritionists, nursing, and medical professionals, are recommended to work closely together to mitigate the impact of disability in MND, including those associated with feeding and swallowing disability (Muscaritoli et al., 2012). The above-mentioned professionals currently lack a sufficient knowledge base to enable the provision of clinical services that are responsive to the characteristics and extent of feeding and swallowing difficulties. Family carers who support home-based care for PwMND concurrently experience both the direct and indirect effects of the illness themselves. Specifically focusing research on the changes family carers experience, encompassed within the context of the mealtime, may enable insight into the consequences of the illness as they impact important events shared within the family unit.

Orientating this study towards family carer experience in MND acknowledges family carer perception as an important avenue that requires attention. Understanding the position of family carers is required in order to achieve a comprehensive understanding of the full extent of the illness, including the psycho-social and psycho-emotional consequences of feeding and swallowing disability. More broadly, information, such as that sought in this study, is essential to enable the planning and provision of healthcare services in a way which appropriately addresses feeding and swallowing impairment as an unavoidable part of this illness.

1.3 Aims and objectives

International MND practice guidance documents (Andersen et al., 2012; Motor Neurone Disease New Zealand [MND NZ], 2022; National Institute for Health and Care Excellence [NICE], 2019; Shoesmith et al., 2020) lack specificity with regards to the management of feeding and swallowing challenges in MND, including the complex psycho-emotional and psycho-social consequences which may arise. HSCPs working with family units impacted by MND may therefore be reliant on their own clinical and/or personal experience of the illness and may make assumptions as to how to implement care when guidelines informing care are lacking.

The current study represents a novel investigation into an area which has received limited research attention to date. The aim of this research was to develop an in-depth understanding of the mealtime experience from the perspective of family carers of PwMND and to generate a conceptual framework accounting for the mealtime changes which occur as a result of MND. A heavily contextualised framework, which specifies key processes underpinning family carer negotiation of mealtimes and involves important micro- (intrinsic) and macro- (extrinsic) causal, contextual, and conditional factors which potentially shape this experience for family carers, will be presented. The framework developed as a result of the analysis of data in this study identifies not only key concepts describing the experience of family carers but also explains relationships which may exist between these concepts in order to explain the behavioural tendencies of family carers. Ultimately, being able to attend to the experience of family carers in the context of feeding, swallowing and mealtime difficulties may help professionals working with families impacted by MND to attend to, interpret, and manage relevant features of family carer experience to improve care outcomes.

The research questions in this study are centred around understanding how family carers negotiate mealtimes following the onset of feeding and swallowing difficulties for PwMND, and uncovering key processes that explain how family carers of PwMND engage in mealtimes with the family members in receipt of their care. The objectives for this study are 1) to identify possible challenges encountered by family carers during mealtimes with PwMND who experience feeding and swallowing difficulties, and 2) to identify how informal caring in MND, specifically during mealtimes, impacts family carers' relationships with care-recipients. This information will contribute to the evidence base on role and relationship changes which can occur within the home-based care dyad in the context of MND and extend understanding of third-party disability in feeding and swallowing

impairment. While the research design of the study reported in this thesis limits generalisability beyond the participants of this study, the insights yielded in this study are expected to be relevant for future studies investigating third-party disability in other populations of family carers of PwMND. In addition, the insights yielded in this study may extend further to the family carers of individuals diagnosed with other progressive neurological illnesses.

1.4 Researcher positionality

Researcher positionality is understood to influence how research is conducted, its outcomes and results (Rowe, 2014), and as such, the researcher's position in the context of this study is declared. The researcher is an Australian-Irish (Australian-trained) SLT with over 20 years of experience working in clinical contexts within the Irish healthcare system. Her experience involves working with people with a wide range of communication and swallowing difficulties including delivering care in the context of the family unit. While the researcher was providing clinical care to an oncology population during this research, her professional experience includes management of disability caused by progressive neurological and palliative illness.

The researcher's motivation to study this area arose from a clinical case in which a family unit was observed to be significantly impacted by the negative consequences of MND-related feeding, swallowing and mealtime-related changes. Management of the psycho-emotional and psycho-social consequences of feeding and swallowing disability were identified by this family unit as priorities for care, yet an evidence base to direct and support the resourcing of care in these domains was not available. The experience of this clinical scenario led to the conception of a pilot study to investigate the experience of feeding, swallowing and mealtime changes for family carers of PwMND (Daly & Jagoe, 2016). This pilot study involved a thematic analysis of semi-structured interview data collected from family carers of people with MND-induced feeding and swallowing disability. The study highlighted highly nuanced, heavily context dependent psycho-emotional and psycho-social consequences of feeding, swallowing and mealtime impairment for this cohort. The relevance of further robust investigation in this area, using a methodology which could support the development of a theoretical basis to guide a social approach to clinical practice was verified through conducting the pilot study.

The researcher's professional biography has shaped her beliefs regarding third-party disability in the context of feeding and swallowing impairment. Preconceptions formed

both in clinical practice via observation of family units impacted by ill-health, and in the pilot study (Daly & Jagoe, 2016), have influenced both her position as a healthcare researcher and her beliefs regarding the impact of disability on the family unit. The researcher is committed to ongoing evidence-based practice and throughout her career has emphasised the importance of authentic, person-centred care; this position is acknowledged to have shaped the researcher's engagement in all stages of the research process. Indeed, the research aims, objectives and questions imply assumptions the researcher has made regarding the significance of this work.

For this study, the researcher situates herself as both an 'outsider' and an 'insider' to the participants being investigated. The researcher was not born in Ireland and presents with a strong Australian accent. This was not overtly raised for discussion by any participant in the study, although accommodations made by the participants (e.g., translation of colloquial language) suggests an influence on the data collected. Having collected data across the 21 participants in this study, it is the researcher's belief that an 'outsider' status in this respect enhanced the participant's sharing of information. A more open disclosure of participant experience was felt to be supported in this instance, perhaps given the perceived risk that participants may share a local social connection with the researcher was lower.

The researcher has no personal experience of providing care for a family member with chronic or palliative illness and no direct experience of the impact of feeding, swallowing and mealtime-related challenges of MND. However, the researcher acknowledges her position as a member of multiple family units (across cultures) and her position in providing care for dependent children within the context of a family unit gives some 'insider' perspective, potentially impacting data handling. Ongoing reflexivity throughout the research process to enhance research quality given the multiple social positions, beliefs and values of researchers (shared by or differing from those of research participants) can influence the research process is required (Holmes, 2020). Reflexivity strategies used by the researcher to enhance quality in light of her own positionality are presented in chapter three of this thesis.

1.5 Thesis structure

This thesis comprises ten chapters. The present chapter (chapter one) introduced MND as a rapidly progressing, incurable neurological illness and has begun to highlight the importance of family carer support in providing home-based care for PwMND. This

chapter has initiated discussion regarding the impact of caregiving for family carers of PwMND and illustrates the relevance of orientating research towards family carers' experiences of feeding, swallowing and mealtime changes in the context of MND. Gaps in the evidence base outlining third-party disability in feeding and swallowing impairment, which impact HSCPs' ability to provide informed and sensitive healthcare interventions, have been identified. The aims and objectives for this study have been set out.

Chapter two of this thesis provides a detailed conceptual overview of available literature pertinent to the multiple areas of interest which have converged in this study. This includes a review of the evidence base describing the profile of illness and optimal management in MND, as well as outlining the models of healthcare considered appropriate in this context (i.e., palliative and family-centred care models). A description of the complexity of the role of family carers involved in supporting feeding and swallowing disability within the general population of people with oropharyngeal dysphagia is provided. The rationale underpinning this study is made clear in chapter two.

Chapter three outlines the methodology and methods selected for this study to capture the experience of feeding, swallowing and mealtime challenges for family carers of PwMND. The researcher's choices regarding the specific research paradigm and the design enacted are described and justified in this chapter. Details of the research methods, including those used to access and recruit participants, as well as collect, analyse, and synthesise the data into the conceptual framework, are provided. Ethical considerations of specific relevance for this study are addressed, and the steps taken by the researcher to ensure quality and rigour are presented for transparency and accountability in chapter three. An overview of the characteristics of the participants in this study is also provided in chapter three.

The findings of the study are presented across three chapters (chapters four, five, and six). Chapter four presents key characteristics of the psycho-emotional landscape within which the feeding, swallowing and mealtime experience of family carers is situated. The key processes the participants in this study engaged in in order to manage the pervasive psycho-emotional challenges of the feeding, swallowing and mealtime difficulties they experienced are described. The relevance of the psycho-emotional context in the enactment of *protecting* (identified as the core category in this study) is illuminated throughout this chapter. Considerations for HSCPs with respect to the processes family carers engage in to mitigate the psycho-emotional consequences of feeding, swallowing and mealtime challenges associated with MND are highlighted in chapter four as

examples of HSCP interactions presenting as barriers and facilitators are presented.

Chapter five presents the core category essential to the framing of family carer action and interaction as they fulfil the roles and responsibilities that arise during the management of feeding, swallowing and mealtime changes within the family unit, *protecting*. This category, at the core of the contextualised framework derived as the end-product in this study, is presented and explained. The applicability of the core category *protecting* in understanding how family carers engage with care-recipients and other individuals involved in supporting the informal care dyad is elucidated in chapter five. In chapter six, the narrative continues, and the conceptual framework representing family carer actions and interactions which may arise in the context of feeding, swallowing and mealtime difficulties is presented. This framework depicts how family caregiving in the management of feeding and swallowing disability was operationalised for participants in this study.

The discussion of findings for this thesis spans chapters seven, eight, and nine. Chapter seven integrates the findings presented in the preceding three chapters and situates this study within the current literature, demonstrating the extent of the contribution made. Chapter eight explores the relevance of the findings of this study as they apply to clinical practice. Implications for future research based on the work completed in this study are outlined in chapter nine.

The final chapter (chapter ten) comprises a critical appraisal of the procedures undertaken in this study. The strengths and weaknesses of this study are identified, and a final reflection by the researcher on this study concludes the thesis.

Chapter Two

Literature review

2.1 Introduction

This chapter provides a conceptual review of the current literature in order to contextualise this study and illustrate the rationale for investigating feeding, swallowing and mealtime changes for family carers of people with Motor Neurone Disease (PwMND). The chapter commences in section 2.2 with an overview of the definition, diagnosis, and classification of Motor Neurone Disease (MND), orientating the reader to this illness. Models for healthcare provision which may be used to underpin health and social care professional (HSCP) management of MND are described, demonstrating the relevance of family-centred models of care in the context of this palliative illness. Section 2.2 brings to light the centrality of healthcare provision which is sensitive to the experience of all individuals impacted by this illness.

Section 2.3 positions family caregiving in MND within the broader context of family caregiving in Ireland. The integral nature of the contribution family carers make in maximising healthcare outcomes in MND is evidenced throughout this section as the impact of caregiving on the individual carer is explored. The wide-ranging roles and often unremitting responsibilities family carers undertake in providing home-based care for family members with MND are introduced in this section, prior to further discussion in the sections that follow.

The nature and extent of disability which can be associated with MND is addressed in section 2.4. Impairments of the ability to self-feed and swallow are emphasised as aligned with the focus of this inquiry. This section reviews evidence regarding feeding and swallowing impairment that is centred on the individual directly impacted by the physiological effect of the disease and to family members who are also impacted by feeding, swallowing and mealtime changes.

Section 2.5 considers third-party disability associated with feeding and swallowing impairment by describing the specific requirements of family carers who assist PwMND to navigate feeding and swallowing difficulties. Gaps in the evidence base explaining the impact of the new roles and responsibilities family carers take on in this area are highlighted.

Section 2.6 introduces the broad theoretical context of the study. Family systems theory (Bowen, 1978) is outlined together with examples of theoretical models relevant to this study's context of this study to demonstrate the meaningfulness of this study. The opportunities and indication for building theory in this substantive area is illuminated in section 2.6.

The chapter concludes in section 2.7 with a discussion which addresses the context of formal healthcare provision for families impacted by MND. Challenges to high-quality care in the area of feeding and swallowing disability, and the importance of the relationships between HSCPs, PwMND and family carers in achieving optimal care are confirmed.

Importantly, the complexity of the relationships formed between HSCPs and members of the family unit, among the members of the multidisciplinary team (MDT), and within the members of the family care dyad is brought to attention throughout this chapter, which concludes by emphasising the significance of feeding, swallowing and mealtime changes for family carers. The obligation for this researcher to investigate the family carer experience of feeding, swallowing and mealtime challenges which occur as a consequence of MND is substantiated in this review of the evidence.

2.2 Motor Neurone Disease: An overview

A broad overview of MND serves to enable the reader to situate feeding and swallowing disabilities within the broader illness context, which is relevant to understanding the family carer perspective. MND is a heterogeneous, multisystem neurodegenerative disease for which currently there is no cure (Hardiman et al., 2011; Masrori & Van Damme, 2020; Phukan et al., 2012). People diagnosed with MND face progressive physical deterioration as motor neurone degeneration leads to weakness of the muscles that enable people to move, speak, swallow, and breathe (Talbot, 2014; Wijesekera & Leigh, 2009). Most PwMND receive their diagnosis 9 to 12 months after the onset of the initial presenting symptoms (McFarlane et al., 2023). The prolonged diagnostic period and aggressive nature of the illness means that by the time of diagnosis, family members have often already commenced tasks consistent with caring roles (Mockford et al., 2006).

The pathophysiology of the illness indicates that a series of losses without relenting periods of disease stability is commonly experienced by PwMND, and many of these losses are shared by members of the wider family unit (Masrori & Van Damme, 2020). The impact of MND on an individual's ability to function independently often calls for family member involvement in disease management (de Wit et al., 2018), and this involvement

has been acknowledged for some time as having far-reaching consequences (Ray & Street, 2006). Given the extensive and often interrelated nature of the impact of MND on families, HSCPs are urged to consider PwMND together with their supporting family members as one unit in the provision of healthcare services (Foley, 2018).

2.2.1 Classification

Different types of MND present and progress in varying ways, and this can influence the demands on and experience of family carers. Classification of MND occurs dependent on the site and severity of the disorder and the pattern of motor neurones involved; this classification is relevant given trends associated with prognosis across subtypes (Statland et al., 2015). When MND is classified according to the type of muscles involved at onset, three main regional subtypes are identified: spinal, bulbar, and respiratory (Kiernan et al., 2011). Spinal-onset MND involves the nerves of the spinal cord and is the most common site of onset (Haverkamp et al., 1995). Initial manifestation of spinal-onset MND is observed in the muscles of the limbs (Masrori & Van Damme, 2020). Difficulty with self-feeding may be detected before swallowing difficulties for individuals who are affected by spinal-onset MND owing to weakness of the muscles of the upper limbs. However, a progression of illness to eventually include swallowing impairment is common (Ruoppollo et al., 2013).

Bulbar-onset MND occurs when brainstem nerves are first affected, with the muscles used for speech, voice and swallowing typically involved at the outset (Masrori & Van Damme, 2020). Common presenting symptoms of bulbar-onset MND include voice and speech changes, nasal regurgitation, oral loss of saliva, and weakness of the tongue (Masrori & Van Damme, 2020). MND of respiratory-onset is rare (McFarlane et al., 2023), with dominant clinical features including dyspnoea, orthopnoea, and overnight hyperventilation on illness presentation (Cheng et al., 2018; McDermott & Shaw, 2008). When the presenting symptoms of MND reflect a combination of spinal, bulbar, and respiratory involvement, the term ‘mixed’ is applied.

The World Health Organisation International Statistical Classification of Diseases and Related Health Problems (ICD-11) (WHO, 2019) is the global standard for illness categorisation. The ICD-11 (WHO, 2019) recognises four main subtypes of MND, outlined in Table 1. The ICD-11 (WHO, 2019) also formally acknowledges MND with extra-motor involvement, given that cognitive changes occur in up to 50% of PwMND (Cheng et al., 2018; Corcia & Gordon, 2012; Phukan et al., 2012; Talbot, 2014). Cognitive changes associated with MND vary in severity and can include frontotemporal dementia (FTD)

(Neary et al., 2005). Approximately 15% of people with MND will meet the criteria for FTD (Strong et al., 2017). The subtype 'ALS with cognitive involvement' is used to classify this in the ICD-11 (WHO, 2019). Recent data from Ireland across the time period 2013 to 2021 indicates that 13% of people fit the criteria for ALS with FTD at the time of their diagnosis (McFarlane et al., 2023).

Table 1.

Sub-types of MND

Sub-type	Frequency	Neurones Involved	Clinical Features	Prognosis/Progression
Amyotrophic Lateral Sclerosis (ALS)	Up to 85% (Román, 1996)	UMN/LMN	Muscle fatigue, atrophy and spasticity	Two to three years median survival time (Statland et al., 2015)
Progressive Bulbar Palsy (PBP)	Up to 25% (Havercamp et al., 1995; Karam et al., 2010)	LMN	Sialorrhoea, dysphagia and dysarthria	Typically rapid progression; less than three years survival time (Chiò et al., 2011; Karam et al., 2010)
Progressive Muscular Atrophy (PMA)	5 to 10% (Kim et al., 2009; Norris et al., 1993)	LMN	Muscle weakness and atrophy in the limbs and trunk	A third of individuals survive over five years and 12% survive more than ten years (Maragakis, 2010; Norris et al., 1993; Visser et al., 2007)
Primary Lateral Sclerosis (PLS)	<5% (Tartaglia et al., 2007).	UMN	Increased muscle tone and muscle spasticity	Survival times of over 14 years reported (Floeter & Mills, 2009; Tartaglia et al., 2007)

Note. UMN (upper motor neurone) refers to motor neurones originating in the cerebral cortex. LMN (lower motor neurone) refers to motor neurones originating in the brainstem and spinal cord (Statland et al., 2015).

Cognitive difficulties and associated behavioural and communication changes can increase the complexity of disease management within a family unit (Watermeyer et al., 2015). The relationship within the family care dyad can become challenged if apathy, disinhibition, and perseveration arise as features of the illness for PwMND (Oliver, 2019; Raaphorst et al., 2012). Reduced empathy, lack of insight and concern of PwMND in respect of their illness and the impact of their illness on others have been identified as features of cognitive and behavioural impairment in MND which can negatively impact

family carers (de Wit et al., 2018; Mendez & Shapira, 2011; Neary et al., 1998). Early detection of cognitive changes is considered paramount in enhancing patient autonomy in relation to healthcare decisions, and family members fulfil an important role in recognising the often subtle changes in these domains (cognitive and behavioural) during the early stages of the illness (Oliver, 2019).

2.2.2 Diagnosis

Diagnosis delivery and the diagnostic process are well-documented as pivotal events for the family unit in MND (Aoun et al., 2018; Galvin et al., 2017). The attitude and approach of healthcare professionals (HCPs) to the diagnostic process has been found to be crucial in the experience of diagnosis for families (Alquati et al., 2022; Galvin et al., 2017). In MND, the diagnostic process can be prolonged given that this is a complex, heterogeneous disease without a single, specific disease biomarker (Logroscino et al., 2008; Yedavalli et al., 2018). Multiple factors in combination, including genetic susceptibility factors and exposure to environmental triggers, are currently hypothesised to cause MND (Al-Chalabi et al., 2014; Logroscino et al., 2008). Confirmation of illness presence by neurologists occurs through identification of progressive UMN and LMN symptoms in case history, clinical, electro-diagnostic (e.g., electromyography and nerve conduction studies), neuroimaging and laboratory studies (Masrori & Van Damme, 2020). Syndromes that closely relate to, or mimic, MND are ruled out in this process. The diagnosis of specific disease sub-types is acknowledged to be challenging, with the initial sub-type diagnosed potentially requiring revision as clinical symptoms evolve (Yedavalli et al., 2018). There is a familial link in up to 13.5% of cases of MND (Andersen & Al-Chalabi, 2011; McFarlane et al., 2023), and in Ireland, this figure has increased significantly over the last 25 years (from 6.6% to 12.6% (McFarlane et al., 2023)). The risk of a genetic predisposition to MND causes additional concern for family members at the time of diagnosis (O'Connor et al., 2018). Genetic testing and genetic counselling in MND have been significant areas of clinical advancement in recent years (Roggenbuck, 2020).

2.2.3 Prognosis and prognostic indicators

The progression of MND can be variable and is impacted by multiple factors (Masrori & Van Damme, 2020). Onset that is spinal, dominant UMN involvement, and a younger age at the time of diagnosis tend to improve the prognosis for PwMND (del Aguila et al., 2003; Haverkamp et al., 1995; Zoccolella et al., 2008a, Zoccolella et al., 2008b). Factors including a rapid progression of symptoms from the time of onset, bulbar symptoms, reduced respiratory capacity, advanced age at the time of diagnosis, co-morbid cognitive

difficulties and poor psycho-social status, tend to negatively impact prognosis (Czaplinski et al., 2006; Johnston et al., 1999; Logroscino et al., 2008; McDonald et al., 1994; Olney et al., 2005; Swash, 2000). Variability in progression of the illness can contribute to uncertainty and loss of control for families impacted by the illness. Uncertainty around how the illness will evolve may negatively impact family carers' ability to plan and prepare for the responsibilities inherent in the caring role, ultimately heightening anxiety, overwhelm and family carer burden (Aoun et al., 2012; Brown, 2003; O'Brien et al., 2012; Ray & Street, 2006; Whitehead et al., 2012).

There is variability in relation to site of onset, age of onset, and rate of progression in MND, and these factors contribute to life expectancy prediction once the diagnosis is made (Chiò et al., 2009). Despite the best available care (both inside and outside the home), the disease trajectory is relentless (Tramonti et al., 2019). The usual cause of death in MND is respiratory failure, which occurs on average two to four years after symptom onset (Andersen et al., 2012; Corcia & Gordon, 2012; Rooney et al., 2013; van Es et al., 2017). Although significant progress has been made in the clinical management of MND with non-invasive ventilation and disease-modifying medication (e.g., riluzole), survival times in Ireland have not changed to reflect these clinical advances (McFarlane et al., 2023). In Ireland, the median survival time is reported as between 14.7 (Rooney et al., 2013) and 16.4 months (O'Toole et al., 2008); this has been steady for the last 25 years (McFarlane et al., 2023).

2.2.4 Tenets of management

Services to support PwMND and their family members call for responsiveness to the individual requirements of the families impacted by the illness rather than an individual's status with regard to progression through the illness stages in isolation (Bede et al., 2011). Within the recommended palliative approach to management (Bede et al., 2011), orientation of healthcare services towards alleviating physical, psychological, and social side effects of the illness to improve the quality of life (QoL) of PwMND and of members of the supporting family unit is encouraged (Andersen et al., 2012). Care centred on and responsive to the needs of family members, combined with care provided by healthcare teams in a multidisciplinary and well-integrated manner across healthcare settings, represents best practice (Hardiman et al., 2002; Talbot et al., 2018). Survival outcomes are enhanced as a result of well-integrated and responsive care (Rooney et al., 2015; Traynor et al., 2003).

2.2.4.1 Multidisciplinary care

Family members, together with PwMND, interface with numerous HSCPs throughout the course of the illness, given the multiple physiological systems impacted by this illness cause numerous disabilities. Expert feeding, swallowing and nutritional management (including counselling of PwMND and their family members relative to gastrostomy placement), recommendation for and advice regarding the use of invasive and non-invasive ventilation (as well as pulmonary hygiene strategies), establishment of intervention addressing mood changes and co-morbid cognitive disorder, facilitation of access to assistive devices, and provision of support in the context of communication impairment (including message and voice banking) are among the roles undertaken by the members of the MDT (Cheng et al., 2018). In the literature, the MDT in MND care typically refers to the specialist MDT centralised in the tertiary care setting. This team is formed by the numerous HSCPs simultaneously involved in care and is led by a consultant neurologist with a special interest in MND (Cheng et al., 2018). In Ireland, 80% of PwMND attend one national specialist MND clinic (McFarlane et al., 2023). Together with their family members, PwMND attend this clinic approximately every 2 to 3 months (Hardiman et al., 2021); consistent with the recommendations in international practice guidelines (NICE, 2019). The significance of the MDT in reducing hospitalisation, disability and prolonging survival has been documented (Chiò et al., 2006a; Ng et al., 2009; Traynor et al., 2003). The positive impact of specialist MDTs on reducing healthcare costs associated with MND has also been documented, which is significant given that the median cost of formal health and social care for a PwMND is estimated to be 21,540 euro per year (Connolly et al., 2015). The subjective outcomes of MDT care, encompassing the impact on the QoL and wellbeing of PwMND and their family members, have not been studied comprehensively. The goals, expectations, standards, and concerns of families impacted by MND with respect to specialist MDT care warrant further investigation.

Since 2001 in Ireland, a shift away from the provision of healthcare within acute services towards care based in the community has been driven by Department of Health Primary Care Strategy (Department of Health, 2001); this is reinforced within the current Department of Health and Health Service Executive (HSE) strategy (Department of Health, 2021; HSE, 2023). Healthcare for PwMND and their families is accessed not only via HSCPs at specialist MDT clinics but also via supportive services available locally, such as those based at general hospitals, specialist palliative care centres, community and primary care centres, and those available in domiciliary care. Effective delivery of care to PwMND and their family members relies on seamless collaboration, coordination, and

transition across multiple care settings (Hogden et al., 2017). The need for further research attention focused on understanding the barriers and enablers to well-coordinated interprofessional care, particularly in this illness where there are often numerous care transitions across settings, has been highlighted (Hogden et al., 2017).

HSCPs external to the specialist MDT may see families impacted by MND infrequently but may become intensely involved in illness management. This can occur particularly in the late stages of the disease when these HSCPs often access firsthand knowledge about what it is like for the care dyad to manage this illness at home. MDT management of MND via telehealth has gained momentum, but local services inevitably become heavily involved in supporting the intensifying care needs in the late stages of the illness. Worsening health and fatigue can preclude families from travelling to specialist centres to access face-to-face care. HSCPs with highly heterogeneous caseloads in non-specialist centres may have little academic knowledge of palliative care, limited clinical exposure to palliative care populations, and potentially lack specialist mentorship to support work within this area. Limited familiarity with PwMND, combined with the complexities of managing the needs of the PwMND and their family caregivers, may result in confusion and reduced confidence regarding how to proceed with healthcare interventions. In respect of these challenges, Brown (2003) highlighted the risk that potential mismatches between patient and professional preferences for care may arise, particularly if professionals turn to the more traditional focus (catering to the disease rather than the person) given their lack of confidence and experience.

Variable quality of care can arise when comprehensive standards of healthcare practice are not available. Complexity associated with the illness presentation itself, the management options available, and the numerous overlapping care pathways may magnify variability in care. Formal standards of care are required to reduce irregularities in service delivery and ensure consistent quality standards. Algorithms published in European and American practice parameters are available to inform MDT management on many aspects of care (Andersen et al., 2012; Miller et al., 2009a; Miller et al., 2009b). However, the complete myriad of disabilities caused by this illness require attention in clinical practice guidelines to optimise service user experience and HSCP confidence in care. Building on the current guidelines to more comprehensively address the needs of all members of the family unit is important in ensuring both individualised and comprehensive care is achieved.

2.2.4.2 Integration of health services

Multiple agencies are required to enable comprehensive management of all aspects of the illness for the families impacted. Neurology services are involved to offer investigation, diagnosis, modification of the disease process, and management of neurological sequelae; rehabilitation services involve coordinated multidisciplinary interventions to manage disability through assessment, provision of appropriate aids and interventions, and offer practical support; and palliative care services facilitate decision-making regarding end-of-life (EoL) care preferences, manage distressing EoL symptoms, and provide psycho-social support to families (Hardiman et al., 2002). Frameworks for care (such as that suggested in Table 2) are delivered within specialist medical, general hospital, palliative, and primary and community care services. Teams of HSCPs who provide care are required to be flexible and responsive to the complex needs which can present.

Table 2.

Framework for MND Care **(Hardiman et al., 2002)**

Phase of illness	Requirements of healthcare services
Diagnosis: breaking bad news, education and accessing services	Development of disease awareness Reduction in symptoms and distress Establish workable acceptance of the disease Evaluate abilities Assess patient/*family* understanding Access support for *families* and professionals
Disability: coping with progressive disease, accessing specialist care, and availing of treatments	Anticipating needs Avoiding crisis Adaptation of the environment to facilitate activities of daily living Promoting independence Rapid response to control symptoms Consider QoL issues, sexuality, ventilation and EoL decisions
Pre-terminal and terminal: managing increasing disability, maintaining dignity and QoL, alleviating suffering, and introducing advanced care directives	Relieving symptoms and anxiety in patients Maintenance of dignity *Carer/family* support Respect for choice Promotion of autonomy Supporting a peaceful death Bereavement planning and support

Careful communication amongst all team members involved in MND management is required to ensure seamless integration of care, which could otherwise be perceived by the family unit as fractured (Brown, 2003; Hugel et al., 2006). Successful integration of care within a dynamic and evolving illness context can be considered as complex healthcare intervention in and of itself, and particularly in the case of decision-making, it can significantly enrich the care pathway for families (Berlowitz et al., 2023). Mutual enhancement of treatments in MND can occur through well-integrated, interdisciplinary care (Tierney et al., 2019).

2.2.4.3 Quality of life

Optimisation of QoL is a well-known mainstay of care in MND and is the target of intervention for both PwMND and their family members. Shorter survival times and higher rates of mortality are documented for PwMND who are psychologically distressed (McDonald et al., 1994; McLeod & Clarke, 2007; Paillisse et al., 2005). It is challenging to accurately capture the entire range of difficulties which could impact QoL, given that QoL involves a wide range of psychological and existential components to wellbeing; encompassing not only an individual's physiological status but their social, emotional, spiritual, and financial wellbeing (Roger et al., 2014). Measurement of QoL in MND is particularly challenging given QoL can change quickly with any change to individual perspective, level of physical disability, social context, or degree of emotional adaptation to the illness (Foley et al., 2007). In MND, unlike many other progressive neurological illnesses, periods of disease stability are uncommon, and as such, QoL can fluctuate significantly over short periods of time.

Accurate measurement of QoL is required to enable HSCPs to better understand the nature of the impact of feeding and swallowing impairment on QoL and how clinical interactions can influence the QoL of members of the family unit. In clinical practice, there are generic tools available to capture illness-related QoL (e.g., Young et al., 2020). However, as Haraldstad et al. (2019) indicate, multiple conceptual and methodological challenges can arise in QoL measurement, including the sensitivity of QoL measurement tools to detect changes in QoL, the weighting of physical versus existential features in consolidated scoring, and the reliability of aggregated scores in reflecting overall QoL. These factors warrant consideration when using measures of QoL to represent clinical targets or research endpoints.

Obtaining precise information regarding QoL related to specific areas of disability, such as feeding and swallowing disability, may prove even more challenging than more global QoL

measurement. Swallow-related QoL outcomes tools, such as the Swallowing Quality of Life Questionnaire (SWAL-QOL) (McHorney et al., 2002), are available for use with the general dysphagic population, but these tools have not yet been psychometrically tested for use specifically with people impacted by MND. Furthermore, currently available QoL measurement tools are insufficient to provide evidence for those recommended nil per os (NPO) (Hepper et al., 2024). Unique, disease-specific features of MND call for a swallow-related QoL assessment tool which has been standardised for use with PwMND. Additionally, the development of a tool which could be used to capture the impact of third-party feeding and swallowing disability on the QoL of family carers may have benefits extending to both clinical and research settings. An evidence base to inform the development of a QoL measurement tool for use specifically with families impacted by MND is required to facilitate progress towards addressing this important gap.

2.2.4.4 Family-centred care

Family-centred practice in the context of MND involves collaboration between the PwMND, supporting family members and HSCPs in a model of care that is dynamic, individualised, and holistic (Kuo et al., 2012). Family-centred care respects the importance of families in the experience of illnesses and acknowledges the expertise that members of the family unit bring to caregiving. Care structured in this way for individuals with complex difficulties is purported to better suit the needs of key stakeholders in care (MacKean et al., 2005). In a palliative care context, family members are considered central to care. In the context of MND, family members engage with healthcare services not only to support the needs of PwMND but because family carers too have care needs that require the attention of healthcare services. Recommendations in international MND clinical management guidelines (Andersen et al., 2012; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020) reflect the value of family members as part of the MND care triad and go some way to address the needs of these individuals. However, the infrastructure required to provide family-centred care within policy and practice remains limited. Further understanding of the impact of this illness and its multiple associated disabilities (including swallowing and third-party disability related to oropharyngeal dysphagia) is required in order to extend the scope of the practice recommendations, enhance collaboration in therapeutic relationships, and enable the development of policies which promote quality and safety for all involved.

2.3 Family caregiving in Ireland

The terms ‘family carer’ and ‘informal carer’ are often used synonymously to indicate the role of an individual who provides assistance to a family member with some level of care-dependence. This is defined by Harwood et al. (2004) as “the need for human help (or care) beyond that customarily required by a healthy adult” (p. 251). The Care Alliance Ireland (2022) assert that the term ‘informal’ under-represents the extent and quality of the care provided by family members. Objection to the term ‘carer’ has also been voiced by some, given the potential misalignment of this term with social model ideology (Clarke, 2010). How a family is defined is significant within the arena of health, having implications for access to and involvement in healthcare (including healthcare planning) at patient, service, and national level (Whiston et al., 2017). Throughout this thesis, the term ‘family carer’ is used for consistency; the composition, geographic location and functions of the family unit are acknowledged by the researcher to be dynamic and best defined according to each individual’s personal and cultural criteria.

The contribution of family carers can be described quantitatively in relation to the number of hours per week spent completing care-related tasks and the length of time spent in the role of carer; it can also be described by the specific tasks completed by the carer. According to the most recent Irish Census of Population figures (Central Statistics Office, 2022), 299,128 people in Ireland provide unpaid care to others, and this number is rising. 61% of carers in Ireland are reported to be female and 39% male, with over two-thirds of carers aged between 40 and 64 years (Central Statistics Office, 2022). The proportion of carers providing unpaid care in excess of 43 hours per week is documented as having increased from 21% in 2016 to 29% in 2022 (Central Statistics Office, 2022). This figure is also projected to rise.

Accurate statistics regarding the financial contribution of family carers to the state in Ireland are difficult to obtain. However, Family Carers Ireland (2023) (the national charity supporting family carers) have estimated the contribution of family caring as up to 20 billion euro per year when hours spent providing care are costed based on hours which would otherwise be required to fund services in the absence of family carers. Family carers are, in most cases, financially disadvantaged due to the assistance they provide (Family Carers Ireland, 2022), and while the Irish Government has made commitments to improving the support provided to family carers (Department of Health, 2012), minimal progress has been made. The Department of Social Protection currently provides family carers with a fraction of the total cost required to support and address care needs (Russell et al., 2019). However, this financial support is not universal and is provided only if strict

criteria are met (Russell et al., 2019). Reliance on family members to meet individual healthcare needs, given the limited availability of resources within the publicly funded healthcare system in Ireland, is in many cases unavoidable.

In the context of MND, family carers provide the majority of home-based care, with approximately 70% of PwMND cared for at home (Conroy et al., 2021; Corr et al., 1998). Access to supports such as home help and respite services funded through the public sector can be inconsistent (Galvin et al., 2018), and home care services in Ireland have been identified as lacking in policy infrastructure (Murphy et al., 2015; Timonen et al., 2012). Services from the voluntary sector via the Irish Motor Neurone Disease Association (IMNDA) are often required to enable families impacted by MND to meet care needs. Financial support options outside of the carer's allowance are limited, and privately funded (for-profit) home care support is high in cost, rendering it inaccessible to many. While inadequacies in the Irish healthcare system contribute to increased reliance on family members to provide care, many family carers are also financially disadvantaged by taking on caring roles. Family carers are often required to reduce hours spent in paid employment or give up work completely to fulfil the care duties required of them (Russell et al., 2019). This can be especially prevalent when dependency increases and the needs of care-recipients intensify. According to figures presented in an Irish-based MND study on care burden by Conroy and colleagues (2023), family carers spend up to 89.5 hours per week providing care to PwMND as the illness advances. The significant financial burden associated with informal caring in MND has also been identified in studies beyond Ireland (Achtert & Kerkemeyer, 2021).

2.3.1 The value of family carers

Family carers are described as key figures in MND management, given that they provide a significant amount of the support PwMND receive throughout their illness (Conroy et al., 2021). The tasks required of family carers of PwMND are extensive, including the provision of physical, emotional, and psychological support (de Wit et al., 2018; Olsson et al., 2010). Family carers have responsibilities including receiving information from numerous sources, implementing recommendations from multiple agents, acting as advocates, and providing logistical assistance to the recipients of their care (Hogden et al., 2013). Family carers may be decision-making partners for PwMND, deliberating over interventions including life-prolonging interventions such as the potential role for alternative methods of feeding and mechanical ventilation (Hogden et al., 2013). Throughout the trajectory of the illness, family carers may be asked to act on behalf of care-recipients in ways incompatible with their own ethics, morals, and beliefs (Hogden et

al., 2013). This can present complex physical, emotional, and spiritual challenges which may be further complicated in instances where cognitive changes have become part of the profile of illness for the PwMND (Conroy et al., 2021; McCluskey, 2007). Given that the typical preference for PwMND is to remain at home to receive care (Galvin et al., 2020), including EoL care (de Wit et al., 2018), family carers may not only be exposed to, but may be expected to manage distressing symptoms which can arise in the illness trajectory (Aoun, 2004; de Wit et al., 2018; Galvin et al., 2020; Oliver, 1996; Ryan et al., 2012). The assumed responsibility of family carers to manage illness-related complications can occur in the context of what family carers perceive to be insufficient training or ongoing support to do so (Conroy et al., 2023). The complex demands family carers are exposed to, which are inherent in the caring role, can occur while these individuals are engaged in their own process of illness acceptance and adaptation; therefore, the high psycho-emotional and social costs which can result are not unexpected (Conroy et al., 2021; Galvin et al., 2020; Weisser et al., 2015).

2.3.2 Negative outcomes experienced by family carers of people with MND

Caring in MND requires the ability to cope with and adapt to daily changes as well as make long-term adjustments (Olsson et al., 2010), and this extends across the illness and caregiving phases (Hardiman et al., 2002; Penrod et al., 2012; Williams et al., 2008). As such, caregiving can take a toll on the physical, mental and emotional status of family carers (Aoun et al., 2013). The physical and mental health of family carers of PwMND has been found to be substantially below the population norm (Gauthier et al., 2007; Jenkinson et al., 2000), and family carer QoL has been identified as lower than care-recipient QoL in some circumstances (Kaub-Wittemer et al., 2003; Trail et al., 2003). Family carer burden in the context of MND is acknowledged as significant (Hecht et al., 2003; McCluskey, 2007), and this high burden can contribute to physical exhaustion, insomnia, and family carer neglect of self-care (Aoun et al., 2013). The negative impact of family caregiving on financial status, ability to maintain social networks, and the family carer - care-recipient relationship have been highlighted in the literature as factors associated with family carer burden (Hogden et al., 2013). It is notable that family carers may avoid acknowledging the negative outcomes they experience, seeing their own needs as secondary to the needs of the care-recipient (Kennedy et al., 2022), or rejecting the notion that they themselves may be in need of care (Stajduhar, 2003). These beliefs may not be challenged by formal healthcare providers in the administration of care (Penrod et al., 2012), and family carer's reluctance to seek out and accept help may compound their vulnerability to negative health outcomes (Bolmsjö & Hermérn, 2003).

While family carers support PwMND to provide what may fundamentally be considered as an extension of formal healthcare services, they must cope with their own set of losses and the arising physical, psychological, and spiritual care needs (Foley, 2018; McCluskey, 2007). HSCPs and family carers work together to address outcomes of PwMND across all aspects of the disease process. Evidence indicates the relationship between HSCPs and family carers can act as a powerful facilitator or barrier in the management of aspects of the illness understood to be complex and challenging for family carers (Brotherton & Abbott, 2009; Mockford et al., 2006; Paris et al., 2013; Vesey et al., 2008). Given the reliance of HSCPs on family carers to optimise the outcomes of their interventions, a deeper understanding of the perception, position and experience of family carers is required.

2.3.3 Reciprocity of family care in MND

The reciprocity of family care relationships in MND is evident through data indicating correlations which exist between PwMND and their caregivers on measures of depression, anxiety and QoL (Boerner & Mock, 2012; Chiò et al., 2005; Olsson et al., 2010; Rabkin et al., 2000). In describing the integral role of the carer – care-recipient relationship in MND, Chiò et al. (2004, p. 1600) state "the quality of care given by the caregiver(s) and the extent that the patients' social network is considered really supportive are of utmost importance for defining the patients' feelings of well-being". In this way, each family carer – care-recipient dyad could be considered as one psychological unit as well as two separate individuals with needs specific to the roles each party takes on within the care dyad. As Johnson et al. (2017) identified, an assessment of QoL that captures QoL simultaneously for both members of the care dyad may serve as a basis for enhancing open discussion regarding this dynamic and, in turn, support a more family-centred approach to healthcare.

Decisions of importance, such as those regarding life-sustaining treatments and where to access EoL care, are typically made by PwMND within the context of a family unit. One of the principle determining factors in deciding whether to remain at home as the illness progresses (typically preferential for PwMND) is the nature of support available from family carers. The quality of care provided by family carers, which is intrinsically related to carer wellbeing and QoL (Chiò et al., 2015), can influence EoL decisions for PwMND (Clarke et al., 2001; Paris et al., 2013; Simmons et al., 2000). In this way, the facilitators and barriers that influence family carer wellbeing may indirectly impact the wellbeing of PwMND.

PwMND are perceptive to the burden and fatigue experienced by family carers, which for many can be overwhelming (Chiò et al., 2005; Hecht et al., 2003). PwMND may refuse life-sustaining treatments if their QoL is low (Burchardi et al., 2004) and conversely engage in life-prolonging interventions solely out of a sense of obligation to the wider family unit (Foley et al., 2014a; Foley & Hynes, 2018; Greenaway et al., 2015; Martin et al., 2016). Care-related burden studies in MND typically emphasise the burden experienced by family carers which arises due to the series of physical losses MND presents for the recipients of care. However, Foley (2016) encouraged expansion of the conceptualisation of 'caregivers' within the family unit, acknowledging that PwMND also experience a significant burden of care due to the responsibility they continue to have in providing emotional as well as practical support to members of the wider family unit. The bidirectional nature of the care relationship between family carers and PwMND warrants further attention. An exploration of this relationship in the context of the feeding and swallowing difficulties which arise due to MND can illuminate nuances in service user needs as well as opportunities for HSCPs to support the care needs of both members of the care dyad.

2.4 Feeding and swallowing impairment in MND

Most people with MND experience swallowing impairment during the trajectory of their disease with incidence documented as high as 98% for people with bulbar-onset MND (Onesti et al., 2017, Perry et al., 2021). Disorders of swallowing interfere with an individual's ability to move food and fluids safely and efficiently from the mouth, through the pharynx and into the oesophagus and such disorders are termed oropharyngeal dysphagia (Logemann, 1998). This thesis focusses on the impact dysphagia has on the oral and pharyngeal stages of the swallow. Oropharyngeal dysphagia represents one of the most significant complications for PwMND given the potential to cause choking, aspiration pneumonia, malnutrition, and death (Kertschler et al., 2014; Leder et al., 2004; Paris et al., 2013). Studies have identified that swallowing and eating difficulties experienced by PwMND can present one of the greatest sources of anxiety for carers (Trail et al., 2004), and that carer fear of choking as a circumstance of care-recipient death is common (Lisiecka et al., 2020; Neudert et al., 2001; Whitehead et al., 2012). To date, evidence relating to the family experience of oropharyngeal dysphagia in MND has largely been reported as incidental findings from studies focussing on the broader experiences of family carers throughout the progression of the disease. Many of these studies have focused on family carer experiences during the final stages of the illness to better understand carer burden. However, one study of family carers of people with

oropharyngeal dysphagia across multiple aetiologies identified that family carers of spouses with oropharyngeal dysphagia are 2.06 times more likely to experience emotional burden than family carers of spouses without oropharyngeal dysphagia. This is at least in part due to the time consuming nature of dysphagia-related activities restricting opportunities for social involvement, access to social support resources and opportunities for self-care (Shune & Namasivayam-MacDonald, 2020). There is a dearth of research specifically describing the impact of swallowing impairment on family members in the context of progressive neurological illness (Howells et al., 2021). Even more scarce is evidence regarding the impact of feeding dependence on individuals who experience self-feeding difficulties or on the family carers who provide feeding assistance.

2.4.1 Using the International Classification of Functioning, Disability and Health Framework (WHO, 2001) to conceptualise feeding and swallowing disability in MND

The World Health Organisation (WHO) International Classification of Functioning, Disability and Health Framework (ICF) (WHO, 2001) utilises a common language for framing, describing, recording, and measuring the impact of a disease across multiple domains of health. In healthcare, the ICF (WHO, 2001) is generally recognised as the accepted framework for conceptualising illness. In concordance with this universal framework, the swallowing difficulty an individual may experience due to the *physiological* impact of an illness such as MND (e.g., impaired muscle tone affecting musculature required for swallowing), together with resultant *activity* limitations (e.g., decreased ability to meet nutrition, hydration and medication needs orally) and *participation* restrictions (e.g., reduced involvement in mealtimes due to reliance on tube feeding), are presented within a wider context inclusive of *personal* factors (e.g., personal coping style) and *environmental* factors (e.g., availability of social support) to enable an enhanced understanding of the resultant disability.

Although the ICF (WHO, 2001) is applicable across all disabilities, the WHO recognises limitations in using this framework to encapsulate third-party disability, that is, the "disability and functioning of family members…due to the health condition of significant others" (WHO, 2001, p. 251). While the international conceptualisation of disability, through the influence of the ICF (WHO, 2001), has evolved to capture the biopsychosocial components of disability, there has been an acknowledgement that healthcare fields "need time to synthesize what has been learnt" in order to contribute to further meaningful development of the ICF (WHO, 2001) (Madden & Bundy, 2019). The opportunity to address third-party disability more comprehensively in future revised frameworks is

apparent. While further development of the ICF (WHO, 2001) is awaited, factors pertaining to the impact of disability on third-parties can be captured within the *environmental* factors domain of the current framework.

The ICF (WHO, 2001) was established over 20 years ago, yet this framework has not been widely used to categorise oropharyngeal dysphagia. The medical view of oropharyngeal dysphagia, emphasised within the *body structure and function* domain of the ICF (WHO, 2001) (aligned with impairment), continues to dominate conceptualisations of oropharyngeal dysphagia. This is likely due to the overt, readily observable impact swallowing impairments can have on an individual's physical status. However, the purely technical view of the consequences of oropharyngeal dysphagia (orientated to the physiological consequences) has long been challenged on the basis of a recognised inadequacy in using this domain in isolation to capture service user outcomes related to swallowing disability (Threats, 2007). Using the ICF (WHO, 2001) to understand oropharyngeal dysphagia as it impacts all domains of the biopsychosocial model may enhance the ability to comprehensively address the full extent of the disability. Expanding understanding of the human impact of oropharyngeal dysphagia to recognise third-party impact is crucial amongst the wider cohort of people with dysphagia but may be even more important in the context of palliative illnesses such as MND.

The following sections (section 2.4.2, 2.4.3, and 2.4.4) present the evidence base describing known features of swallowing disability which occur secondary to MND. The structure of the presentation of this information is consistent with the categories (domains) of the ICF (WHO, 2001). An awareness of the impact of feeding and swallowing disability across domains is important to support understanding of the experience of feeding and swallowing disability for family carers of PwMND.

2.4.2 Oropharyngeal dysphagia in MND: The nature of the swallowing impairment and the impact on body structure and function

Nearly all PwMND experience impairment of swallow function at some point in the illness (Kűhnlein et al., 2008; Perry et al., 2021). The physical manifestations of the condition depend on the form of MND and how the disease progresses. Involvement of UMNs may result in weakness, spasticity and slow coordination of the lips, tongue, soft palate, jaw, pharynx, and larynx for the individuals affected; involvement of the LMNs in individuals may result in flaccid paresis and atrophy of the muscles supplied by the medulla as well as fasciculations of the tongue (Groher, 1997; Robison et al., 2022; Yorkston et al., 2004). Impairment of swallow function has been reported in the literature across all stages of the

swallow, and in MND is often complicated by respiratory compromise (Miller & Britton, 2011; Plowman et al., 2016).

Numerous studies have demonstrated the functional impact of oropharyngeal dysphagia secondary to MND, which may include reduced ability to swallow saliva, reduced containment of bolus within the oral cavity (anteriorly and posteriorly), reduced efficiency of mastication, inefficient bolus formation and transport, reduced oral clearance, reduced pharyngeal clearance, incomplete airway protection, nasal penetration, delayed initiation of pharyngeal phase, penetration of food and fluids into the airway, and aspiration (D'Ottaviano et al., 2013; Easterling et al., 2013; Kent, 2012; Kűhnlein et al., 2008; Robison et al., 2022; Waito et al., 2018). Dysphagic symptoms in MND have been found to be exacerbated by co-occurring respiratory dysfunction, which often involves a weakened cough response (Kűhnlein et al., 2008). Specifically in relation to aspiration (entry of food/fluid into the airway below the true vocal folds), Gaziano et al. (2015) identified that the majority (55%) of PwMND who aspirate do so silently. The traditional understanding that sensory functions are spared in MND has been challenged by the findings from this and other studies investigating laryngeal sensation (Robison et al., 2022; Ruoppollo et al., 2016) and sensory deficits in the larynx are now documented as a contributing factor to dysphagia severity.

In a systematic review, Waito et al. (2017) found the following physiological features to be consistent with MND: reduced isometric tongue strength, reduced lingual thickness, reduced or disorganised tongue movements during swallowing, reduced hyolaryngeal movement, incomplete laryngeal closure, longer duration of swallow, discoordination between timing of laryngeal excursion and cricopharyngeal relaxation, reduced voluntary cough airflow, reduced respiratory-swallow coordination and reduced swallow pressures. Additionally, Waito et al. (2018) identified reduced pharyngeal contraction as a consistent feature of presentation for dysphagic individuals with MND. Further advances in instrumental assessment of swallowing (e.g., with high-resolution pharyngeal manometry) have the potential to further enhance our understanding of the physiological changes to swallow caused by MND (Diver & Regan, 2022).

The body of evidence relating to the physiological consequences of oropharyngeal dysphagia in the context of MND continues to grow. Desport et al. (2000) document swallowing dysfunction as a major cause of nutritional decline for PwMND and Muscaritoli et al. (2012) document malnutrition as a negative prognostic factor in MND due to its potential to worsen neuromuscular state. Desport et al. (1999) found a 7.7 times increased risk of death in malnourished individuals with MND. For PwMND, broncho- and

aspiration pneumonia are leading contributors to death (Corcia et al., 2008). Early identification of PwMND who are experiencing changes in swallow function is key to preventing negative physiological consequences. However, formal swallow screening protocols have not been internationally agreed upon (Pattee et al., 2019), and initial swallowing symptoms in this population may be under-reported (Lisiecka et al., 2021; Onesti et al., 2017). Lisiecka and colleagues (2021) hypothesise that swallowing difficulties localised to the oral stages may not be considered significant by PwMND and Onesti et al. (2017) consider that a progressive adaptation to slowly deteriorating bulbar function may contribute to an inability for PwMND to self-detect swallowing difficulties in the early stages. Given the reduced reliability of self-detection of early signs of swallow dysfunction, HSCPs may rely on the reports of family members to assist with the identification of early changes to swallow function.

Difficulty in the ability to tolerate a full range of food and fluid consistencies is common for PwMND (Dand & Sakel, 2010; Paris et al., 2013). Fatigue during oral intake can be related to prolonged eating duration and may exacerbate physiological impairment of swallow function (Kent, 2012). Fatigue may also contribute to difficulties with self-feeding given the impact on strength and dexterity in the upper limbs (McDermott & Shaw, 2008), and in these situations, reliance on family members for assistance may arise. An array of difficulties with mealtimes can become apparent for individuals who experience cognitive decline as part of their clinical profile; altered eating habits, altered food preferences and behavioural disinhibition can impact swallowing and mealtimes, particularly for individuals with co-occurring FTD (Ahmed et al., 2016; Ikeda et al., 2002; Woolley et al., 2007). PwMND may require assistance to optimise food and fluid intake, and non-oral methods of feeding may be required if oral intake is unsafe or inefficient in meeting nutrition, hydration, and medication needs. Enteral feeding (feeding into the gastrointestinal tract using a tube) has been the subject of significant attention in the research given the ethical and moral considerations associated with this intervention. Clinical guidelines from the European Federation of the Neurological Sciences (Anderson et al., 2012) and the American Academy of Neurologists (Miller et al., 2009a) are available to direct decision-making regarding enteral methods of feeding to standardise care in this area. However, evidence on the survival and nutritional benefits of gastrostomy feeding remains contradictory.

Emotional responses which arise for PwMND due to the onset of oropharyngeal dysphagia can be represented within the *mental functions* category of the *body functions* component of the ICF (WHO, 2001). Evidence drawn from the general clinical population

suggests oropharyngeal dysphagia and fear of the onset of complications associated with oropharyngeal dysphagia cause anxiety and distress for individuals who experience disability in this area (Verdonschot et al., 2013). Swallowing impairment in a general dysphagic clinical population has been found to negatively impact self-esteem and QoL (Cichero & Altman, 2012; Ekberg et al., 2002; Paris et al., 2013), causing embarrassment, discomfort and reduced self-confidence (Farri, 2007). Similar to the findings from this general population, negative psycho-emotional outcomes associated with feeding and swallowing impairment have also been reported for PwMND. Anxiety, fear (particularly regarding choking and respiratory decline), frustration, embarrassment, isolation, and depression have all been associated with oropharyngeal dysphagia for those with MND (Lisiecka et al., 2021; Paris et al., 2013; Tabor et al., 2016; To et al., 2018).

2.4.3 Oropharyngeal dysphagia in MND: Impact on activity and participation

There is a paucity of research addressing the psycho-social consequences of feeding and swallowing impairment specifically as a result of activity and participation limitations caused by oropharyngeal dysphagia for PwMND. Acknowledging the function of eating and drinking as a social act and focusing on feeding and swallowing impairment secondary to MND in this manner is required to enable HSCPs, service planners, and policy makers to develop a more extensive understanding of the impact of this disability. Including psycho-social aspects of oropharyngeal dysphagia in disability conceptualisation is necessary so that management strategies designed to meet the needs and expectations of PwMND and their supporting family members can be fully realised. The presence of oropharyngeal dysphagia has been identified as having the potential to induce negative psycho-social consequences, which may include the altering of relationships, identity, and sense of group membership, in addition to an individual's ability to participate in socio-cultural experiences (Kenny, 2015). The impact on psycho-social function due to the presence of feeding and swallowing impairment for people with progressive neurological illnesses such as Parkinson's disease (Howells et al., 2021; Plowman-Prine et al., 2009) and multiple sclerosis (Alali et al., 2018), has been identified. Additionally, in head and neck oncology studies, altered interpersonal interaction and relationships as well as reduced ability to participate in community, social and civil life have been noted as consequences of swallowing difficulties (Dornan et al., 2021).

The majority of what is known about the psycho-social impact of oropharyngeal dysphagia in MND has been learned from a limited number of quantitative studies evaluating swallow-related QoL for individuals directly impacted by the illness, primarily using the SWAL-QOL questionnaire (McHorney et al., 2002) (da Costa Franceschini & Mourão,

2015; Paris et al., 2013; Tabor et al., 2016; To et al., 2018). The SWAL-QOL is a non-disease specific, self-report tool comprising 44 statements grouped into 10 lifestyle scales: food selection, burden, mental health, social functioning, fear, eating duration, eating desire, communication, sleep, and fatigue. Swallow-related QoL using the SWAL-QOL reflects status across all domains of the ICF (WHO, 2001). By using this tool, Paris et al. (2013) identified that social health could be impacted by the onset of oropharyngeal dysphagia for PwMND. The social impact of oropharyngeal dysphagia for PwMND in this study included limitations in food selection, increased eating duration and decreased eating desire. Eating duration and social life were found to be significantly impacted by the presence of oropharyngeal dysphagia in a study by da Costa Franceschini and Mourão (2015), which involved administration of the SWAL-QOL to individuals with ALS of spinal onset. Tabor et al. (2016) also identified a reduction in meaningful engagement in social activities coinciding with the presence of oropharyngeal dysphagia for PwMND by using the SWAL-QOL (McHorney et al., 2002). In the same study, reduced socialisation in people with oropharyngeal dysphagia who were aspirating, leading to feelings of isolation and helplessness was identified. The SWAL-QOL (McHorney et al., 2002) was also used by To and colleagues (2018) in a study which reinforced the findings from the early study by Tabor et al. (2016), whereby participants reported reduced willingness to dine in public spaces and engage in social activities due to oropharyngeal dysphagia.

While the SWAL-QOL (McHorney et al., 2002) is often the preferred choice of QoL outcome tool for use with individuals with progressive neurological dysphagia (Keage et al., 2015), this tool is not without limitations. The pre-defined question set included in the SWAL-QOL is unable to address the full range of psycho-social implications of swallowing impairment, and these psycho-social changes which can occur with the presence of feeding and swallowing impairment may significantly impact QoL. The nuanced, subjective construction of QoL arguably warrants a measurement tool or process that has the sensitivity to reflect the highly personal nature of this construct through precise evaluation of the domains an individual identifies as most important or meaningful to them. Qualitative approaches are uniquely placed to achieve this. However, to date, qualitative studies in this area have been limited. In the only qualitative study published on the experience of swallowing impairment for PwMND to date, Lisiecka et al. (2021) utilised an interpretive phenomenological analysis approach to investigate the dysphagia experience for 10 PwMND. The work of Lisiecka and colleagues (2021) supported previous findings from quantitative studies relative to the experience of social isolation for PwMND with oropharyngeal dysphagia. Lisiecka et al. (2021) described avoidance of eating in public as a strategy used by PwMND to navigate impairment of swallowing. Data from more

narrowly focused qualitative studies investigating the experience of enteral feeding for PwMND (e.g., Stavroulakis et al., 2014; Stavroulakis et al., 2016) has also highlighted the impact of feeding and swallowing impairment on social aspects of life for PwMND.

Currently, we lack comprehensive evidence in respect of facilitators and barriers to social functioning in the context of MND-related oropharyngeal dysphagia. The unique perspective of family members who may themselves act as enablers or disablers in the disability experience has yet to be investigated in-depth using qualitative methods. The current evidence base in this area is restricted to one published (descriptive) study focused on family carers of PwMND (Lisiecka et al., 2020). This study by Lisiecka et al. (2020) presented themes from an interpretive phenomenological analysis conducted on semi-structured interviews with 10 family carers of PwMND with oropharyngeal dysphagia. The study identified that family caregiving in the context of swallowing impairment is predominantly characterised by *transformation,* which encompasses *emotional* transformation (aligned with distress) as well as a *transformation of the mealtime experience* given the new roles and responsibilities required of family caregivers. Lisiecka et al. (2020) described social changes family carers experience due to the presence of swallow disability. Family carer discomfort when eating in public (given care-recipient dysphagia) was identified, as was the potential risk that mealtimes could pivot from being an enjoyable (social) experience to one involving care demands and subsequent burden. The desire of the family carer to protect care-recipient safety in the context of swallowing impairment contributed to the mealtime transformation experienced (Lisiecka et al., 2020). The specific impact of feeding dependency on the family carer was not described nor explained in this study.

In clinical practice currently, there are no tools specifically designed to investigate the impact of feeding, swallowing and mealtime change on family carers of PwMND. According to DeRenzo (1997), the ability to eat and drink, and the meanings we attach to food, are deeply connected to the activities and experiences we value most. These mealtime-related activities are integral to how we view ourselves both individually and in relation to others, and can be highly significant within family units. The processes used by family carers in managing the psycho-social changes that are unavoidable with the onset of feeding and swallowing difficulties in the context of MND warrant focused research attention.

2.4.4 Oropharyngeal dysphagia in MND: Considering contextual factors which contribute to the experience of disability

Based on personal and environmental factors, experiences of disability can alter. Using the personal and environmental domains of the ICF (WHO, 2001) to frame understanding of the impact of context on the severity of feeding and swallowing disorders can help orientate clinicians and researchers to the depth, complexity, and multifaceted nature of feeding and swallowing impairments. Through consideration of contextual conditions pertinent in the extent to which feeding and swallowing disabilities are experienced by PwMND, an awareness of the role of family carers in how the disability can be experienced is raised. Indeed, the familial context is integral to how people with feeding and swallowing disabilities secondary to MND experience and interpret their disability (Nund et al., 2015).

In the absence of formal representation of third-party disability within the current ICF (WHO, 2001), the impact of feeding and swallowing disability on the third-party is represented within the contextual domains (i.e., *personal* and *environmental* factors) of the framework, the person directly impacted by the physiological consequences of the impairment is centralised and family carers are not addressed as independent agents. Further evidence is required to comprehensively realise the real-life extent of feeding and swallowing disabilities by encompassing all the individuals who may be impacted by feeding and swallowing disability.

The following sections (section 2.4.4.1 and section 2.4.4.2) set out evidence regarding contextual factors, including personal and environmental barriers and facilitators, known to be of relevance in the experience of feeding and swallowing disability for PwMND. The emerging evidence base requires further systematic interrogation and expansion beyond the PwMND to identify contextual factors relevant for family carers who experience third-party disability as a consequence of feeding, swallowing and mealtime impairment.

2.4.4.1 Personal factors

Personal coping styles and personality factors have a bearing on how disability is experienced by the individual; this is framed by the *personal factors* domain of the ICF (WHO, 2001). Personal factors which may increase or reduce the severity of feeding and swallowing disability in MND have not been comprehensively addressed in current research. The influence of personal factors, including demographic factors (e.g., socio-economic status, race and age), personality, beliefs and attitudes of PwMND regarding

their experience of feeding and swallowing disability warrants research attention. These factors have an influential role in shaping the whole illness experience in MND (Ng & Khan, 2011). Studies in populations such as dementia (Gustaffson et al., 2003) and head and neck oncology (Ninfa et al., 2023) have demonstrated the relevance of considering personal factors when attempting to understand feeding and swallowing disability.

While not studied systematically, the relevance of personal coping strategies in the experience of oropharyngeal dysphagia has been implicated in the findings of a small number of qualitative studies. Lisiecka et al. (2021) referenced two strategies used by PwMND to cope with and adjust to swallowing difficulties: *living in the here and now* and *maintaining control* (of the management of the disability) *by avoiding professional management of oropharyngeal dysphagia*. These strategies have also been documented in studies investigating coping within the wider context of the illness (Centers, 2001; Costa et al., 2021; Gale, 2015; Greenaway et al., 2015; Olesen et al., 2022). Being able to independently apply compensatory strategies to overcome the physiological impairment of swallowing (e.g., positioning the bolus at the posterior of the oral cavity, taking tablets with other foods such as porridge, avoiding troublesome diet items) appears to enable PwMND a sense of control over feeding and swallowing disability (Lisiecka et al., 2021). A retained sense of control has been identified as mitigating the negative psycho-emotional and psycho-social consequences of oropharyngeal dysphagia in head and neck oncology studies (Dornan et al., 2021). An individual's tendency towards and ability to use cognitive strategies such as *believing someone else is worse off* have also been highlighted as potentially advantageous in reducing the impact of swallowing disability for people within the head and neck oncology population (Nund et al., 2014a).

An individual's belief system, particularly how they perceive disability, is a personal factor of relevance in understanding the impact of feeding and swallowing disability in MND. In two studies focused on gastrostomy decision-making for PwMND, Pols and Limburg (2016) and van Eenennaam and colleagues (2023) highlighted that the meanings PwMND attach to their bodies could be associated with a sense of self. Pols and Limburg (2016) outlined that a PwMND's perspective regarding what they considered to be a *natural* versus an *unnatural* body could influence the acceptability of gastrostomy. Beliefs around disfigurement and the degree of aversion to the presence of a gastrostomy tube within the body could present a reason for gastrostomy rejection. In the van Eenennaam et al. (2023) study, personal factors such as an individual's level of acceptance, adaptation capacity, and sense of control and agency could influence gastrostomy decisions, and this could ultimately affect an individual's experience of swallowing disability. Indeed, as Labra

et al. (2020) described, an individual's perception regarding the care demands required of family carers to support gastrostomy tube feeding could influence gastrostomy decisions. Preferences regarding engaging in interventions which would prolong the period of disability could also be linked to an individual's conceptualisation of disability and what it might mean to be disabled.

Further research aimed at uncovering adaptation and coping strategies PwMND use in the context of oropharyngeal dysphagia is required to deepen understanding of how these individuals navigate feeding and swallowing disability. Further research is also required to guide healthcare assessment, education and support, in order to limit the adverse impact of feeding and swallowing disability for PwMND.

2.4.4.2 Environmental factors

An appreciation of how people with swallowing impairment engage in mealtimes with a range of people in different mealtime environments is required in order to understand the impact of swallowing disability (Balandin et al., 2009). Systematic assessment of the environment and environmental factors which can facilitate or obstruct the functioning of PwMND with feeding and swallowing disability is not common in clinical practice and has not yet been foregrounded in MND-related research to date.

Environmental factors such as the level of background noise, privacy of seating location, availability of service staff to assist with off-menu dysphagia diet-related requests, and choice of menu items (including condiments) available within restaurant and café settings have been described as potential influences on the success of social eating in head and neck oncology-related dysphagia studies (Dornan et al., 2021; Dornan et al., 2022). Within the field of progressive neurological illness, Herke et al. (2018) in a Cochrane review of evidence regarding the environmental factors that influence diet and fluid intake for people with dementia, could not identify environmental factors supportive of function given the low quality of limited evidence available in the area. As yet, the characteristics of a "dysphagia-friendly" environment design that are most relevant in enhancing social eating and drinking for PwMND have not been described.

With respect to the ICF (WHO, 2001), it is the social and relational features of a dysphagic individual's environment which potentially perpetuate or ameliorate feeding and swallowing disability that have received most attention. Family members are acknowledged as one of the most significant sources of support for people with feeding and swallowing difficulty (Dornan et al., 2021; Nund et al., 2015), and the attitudes of

family carers can significantly influence the experience of the illness (positively or negatively) through enablement or disablement (WHO, 2001). Head and neck oncology-based studies dominate the literature in this area. In head and neck oncology-related oropharyngeal dysphagia, relationship changes that have been characterised as both positive (e.g., increased bonding) and negative (e.g., relationship strain) have been described (Patterson et al., 2013). The attitude of family carers towards the caregiving role, family carer capacity to problem solve difficulties, and availability of family carer resources (e.g., financial, social, and emotional) to support people with feeding, swallowing and mealtime impairment have been identified as potential sources of influence on the disability experience (Howells et al., 2021; Nund et al., 2014b; Nund et al., 2015). Given the significant role of family carers in the experience of disability and disease management, it is important to consider the position of these individuals with respect to the third-party impact of disability.

The impact of feeding and swallowing impairment on members of the family unit is under-studied in MND research. Evidence relating to carers' lived experience of oropharyngeal dysphagia management in the context of long-term illness provides some insight into the challenges faced by family carers in this area of disability. A small number of studies, primarily in stroke and head and neck oncology, describe the family carer role in relation to the provision of feeding, swallowing and mealtime support (Johansson & Johansson, 2009; Nund et al., 2014b; Patterson et al., 2013; Penner et al., 2012). These studies highlight behavioural changes required of family carers due to the onset of oropharyngeal dysphagia for their family members (Johansson & Johansson, 2009; Nund et al., 2014b; Patterson et al., 2013; Penner et al., 2012). Reduced family carer participation in social situations, restrictions on family carer's own diets imposed through changes in care-recipient circumstances, eating in secret due to feelings of guilt or discomfort, and a tendency to snack frequently rather than eat full meals due to a lack of time for self-care have been identified (Johansson & Johansson, 2009; Nund et al., 2014b; Patterson et al., 2013; Penner et al., 2012). Some studies report negative psycho-emotional consequences (e.g., anxiety and helplessness) experienced by family carers associated with feeling ill-prepared to undertake the roles and responsibilities associated with the complex demands of dysphagia management (Nund et al., 2014b; Patterson et al., 2013; Penner et al., 2012). Given these studies utilise descriptive research designs, explanations regarding the psycho-social processes that underpin the behavioural changes family carers make in the presence of feeding and swallowing disability within the family unit, necessary to inform clinical practice, are not possible. Further studies using research methodologies that enable explanation, and enhance HSCP's ability to predict

the behavioural tendencies of family carers on the basis of key contextual and conditional factors, such as afforded in grounded theory (GT) studies, are required to build the evidence base.

Family carer burden studies emphasising burden associated with oropharyngeal dysphagia foreground the demands on family carers associated with gastrostomy and the management of tube feeding (Brotherton & Abbott, 2009; Greenaway et al., 2015; Martin et al., 2016; Stavroulakis et al., 2016; van Eenennaam et al., 2023; Vesey et al., 2008). The significance of family carer support provided to PwMND in order that they may maintain a sense of control, choice and autonomy when navigating decisions regarding gastrostomy feeding has been described (van Eenennaam et al., 2023). Restrictions on carer participation in mealtimes due to the need for gastrostomy feeding and changes in intimate spousal and other family relationships secondary to the presence of oropharyngeal dysphagia are documented as a source of strain for family carers (Lisiecka et al., 2020; Nund et al., 2015; Stavroulakis et al., 2016). Extending beyond the focus of gastrostomy experiences, the relationship between family members, family carers and PwMND in the context of feeding and swallowing changes has not yet been extensively evaluated. HSCPs are not able to use a body of evidence to predict features of relationships that may influence how feeding and swallowing difficulties are experienced. The psycho-social and psycho-emotional impact of oropharyngeal dysphagia on family carers of PwMND is not well known, and as such, HSCPs working within this area risk failing to recognise and address these important difficulties and concerns for service users. Given that mealtimes are a regular social activity typically involving multiple members of a family unit which fulfil many health and wellbeing-related functions (Dunbar, 2017), further research from the perspective of family members is required to support optimal maintenance of these functions.

Within the environmental factors domain of the ICF (WHO, 2001), which, according to Threats (2007), “can make the difference between living successfully with dysphagia and dire physical and social consequences” (p. 329), are supports, including the support provided by HSCPs. The importance of the dynamic between HSCPs and family members providing care for PwMND has been highlighted in qualitative studies (e.g., Foley et al., 2014a). However, the relationship between PwMND, family carers and HSCPs in managing feeding and swallowing disability has not yet been investigated. Generalisation of research focused on highly specific care situations (such as gastrostomy decision-making), other clinical populations (such as head and neck oncology), or HSCP’s reliance on their clinical experience alone to direct care is inadequate to meet the needs of the

family unit. HSCPs working with PwMND and family carers in the context of oropharyngeal dysphagia management require evidence to underpin care practices and inform HSCPs on the wide range of sensitivities that may be required for the successful administration of care.

2.4.5 Management of oropharyngeal dysphagia: The context of healthcare professionals

As detailed in sections 2.2.4, 2.2.4.1, and 2.2.4.2, the provision of healthcare services for PwMND and their family members involves complex, challenging multi-professional pathways aimed at meeting individual needs which evolve constantly as the disease progresses (Muscaritoli et al., 2012). The provision of care specifically for those experiencing feeding and swallowing difficulties due to MND is no exception. Speech and Language Therapists (SLTs) are the primary professionals responsible for the provision of clinical services to individuals with oropharyngeal dysphagia (Ashford et al., 2009; Kent, 2012). However, professional management of feeding and swallowing disability is supported by a much wider team of HSCPs, including occupational therapists, clinical nutritionists, pharmacists as well as nursing and medical staff. SLT practice guidelines are available to direct management in the realm of feeding and swallowing difficulties (e.g., Irish Association of Speech and Language Therapists [IASLT], 2022). However, these dysphagia practice guidelines are applicable to a general clinical population and lack specific information regarding the management of complex aspects of care which can arise in family units impacted by MND, including the negotiation of mealtimes in the presence of feeding and swallowing disability. No formal clinical guidelines directing the practice of SLTs in the context of palliative illnesses are available in Ireland. Internationally, the role of the SLT in oropharyngeal dysphagia management in the context of MND is not specifically defined. Work to establish a globally recognised best practice guideline on the management of bulbar dysfunction for PwMND is in progress but not yet formalised (Pattee et al., 2019), and further direction on how to facilitate family carers who extend the interventions of HSCPs in the home, as well as regarding how to facilitate family carers who are impacted by feeding and swallowing impairment as third parties is required.

In the absence of comprehensive guidelines directing clinical management of feeding and swallowing difficulties for PwMND and the supporting family unit, the wider body of literature may guide HSCPs. Historically, the literature has documented management strategies that focus on maximising the safety and efficiency of oral intake for PwMND rather than those that address the social impact of the feeding and swallowing

impairment. In the early stages of illness, management strategies which have been described include early detection of oropharyngeal dysphagia via screening, and establishment of baseline levels of function via clinical and instrumental assessment (primarily utilising video fluoroscopic and flexible endoscopic methods of evaluation). SLTs, together with other HSCPs, provide education and counselling to both PwMND and supporting family members regarding feeding and swallowing and the nature of the impairment (across domains) in order to reduce any associated complication from the early stages of illness presentation (Rogus-Pulia & Plowman, 2020). The impact of the education and counselling process and the establishment of early HSCP expectations relative to family care on family caregiver burden has yet to be described in the research and warrants attention.

As MND advances, interventions based on behavioural change and compensatory strategies (e.g., modification and avoidance of food and fluid consistencies, postural adjustments and environmental changes to maximise swallow safety) are commonly recommended by HSCPs (Kent, 2012; McDermott & Shaw, 2008; Strand et al., 1996). Rehabilitation approaches involving exercise for muscle strength and resistance have traditionally been avoided by SLTs due to concerns regarding the potential exacerbation of muscle fatigue (Epps et al., 2020; Walshe, 2014). However, the potential for early rehabilitation of specific physiological components of the swallow mechanism to improve physiological reserve is now being explored (Plowman et al., 2015), and preliminary findings on expiratory muscle strength training have given some optimism (Plowman et al., 2019). Further advances in management may lead to an increased expectation from HSCPs on family carers supporting home-based implementation.

In the late stages, MND care outlined in the context of oropharyngeal dysphagia is orientated towards maximising swallow function, preventing deterioration of pulmonary status, maximising oral hygiene, and optimising nutrition and hydration (Rogus-Pulia & Plowman, 2020). Alternative feeding methods are often appropriate to consider, with decisions regarding whether to proceed with enteral feeding or forego active treatment for terminal palliative care acknowledged as both complex and challenging (Kent, 2012; McCluskey, 2007; Strand et al., 1996). Evidence to support the life-prolonging effect of enteral feeding for PwMND is inconclusive given that no randomised controlled trials (RCTs) or quasi-RCTs are available to indicate whether enteral tube feeding is more effective than continued oral feeding (Sulistyo et al., 2023). Section 2.4.4.2 has highlighted enteral feeding as a source of significant burden for family caregivers.

Guidelines on the management of the psycho-social and psycho-emotional dimensions of oropharyngeal dysphagia in MND have not been formally developed, and evidence to inform this process remain scarce. Waito et al. (2017) highlighted the scarcity of research attention designated to the management of psycho-social and psycho-emotional consequences of oropharyngeal dysphagia in MND in a scoping review describing dysphagia management in MND (see Table 3).

Table 3.

***Oropharyngeal Dysphagia Management Options Reported in the Literature* (Waito et al., 2017)**

Management option	Frequency
Enteral nutrition	63.1%
Dietary and texture modification	40.8%
Rehabilitation/compensatory strategies	37.6%
Treatment for cricopharyngeal dysfunction	14.0%
Treatment to optimise secretion management	10.8%
Other (e.g., pharmaceutical/prosthetic)	7.6%

Strategies targeting participation and wellbeing, and those which consider important extrinsic (environmental) and intrinsic (personal) factors in oropharyngeal dysphagia management were identified as in need of attention in this review. Clinical management guidelines for MND acknowledge the importance of psycho-social and psycho-emotional aspects of care (MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020). However, detailed guidelines, which are essential infrastructure required to support the translation of clinical management recommendations into actions, are lacking. Research specifically designed to evaluate the needs of PwMND and their family members, and that may uncover successful strategies used in dysphagia management is required.

2.5 Family carers and the extent of third-party disability in feeding and swallowing Impairment

The role of family carers in feeding and swallowing management in MND often involves the direct provision of assistance with oral intake, and feeding assistance in isolation has been evidenced as a task of great magnitude involving considerable resources, both physical and emotional (Chiò et al., 2006b; Johansson & Johansson, 2009). The

responsibilities of family carers have been documented as including early reporting of feeding and swallowing difficulties; monitoring food and fluid intake; preparation and provision of food with regard to its nutritional content, texture and food preferences; management of enteral nutrition and complications which can arise due to both oral and enteral feeding; and motivating care-recipients to eat, drink and adopt the safe feeding strategies recommended by HSCPs (Onesti et al., 2017; Patterson et al., 2013). Moving beyond descriptions of practical tasks, there has not been an in-depth examination as to what effects these new responsibilities and roles within the family unit may have and how they are managed. SLTs currently lack knowledge regarding what is important to PwMND and their family carers when engaging with services designed to manage feeding and swallowing-related difficulties. Hence, further investigation is necessary to better understand the family carer experience, and enable SLTs as well as other HSCPs working in dysphagia to provide care that is sensitive not only to the person directly impacted by the illness but also to family carers.

2.6 Theoretical context of the current study

Theory specifically accounting for the feeding, swallowing and mealtime experiences of family carers of PwMND is not yet available; this study represents a nascent, exploratory investigation of a previously understudied area. The study is aligned with the ideology of social models of health, which acknowledge wider social determinants impacting physical, emotional and social health and wellbeing (Rahman et al., 2024). The study seeks to improve the effectiveness of healthcare intervention for both PwMND and family carers within the context of a wider family unit by enhancing understanding regarding feeding, swallowing and mealtime disability in MND. By obtaining an understanding of the experience of MND-induced feeding, swallowing and mealtime challenges from the perspective of family carers, the ability to observe, measure and intervene to improve the psycho-social and psycho-emotional consequences of feeding and swallowing disability can be enhanced.

Given no formal theory specific to the area under investigation has been published to date, this study did not attempt to confirm or expand on current theory. Rather, this study aimed to develop a conceptual framework on which to build theory and guide clinical practice. This study crosses multiple clinical areas (e.g., palliative illness, progressive neurological illness) and investigates mealtimes which can be understood as multifaceted events given the inherent biological, social and cultural parameters of mealtime situations.

While the chosen methodology for this study, GT (Corbin & Strauss, 2008/2015), promotes caution regarding researcher engagement with theory at the outset of a study

(to reduce potential theoretical contamination given the inductive nature of GT (Green, 2014; Luckerhoff & Guillemette, 2011)), the research question in this study is situated within a broad theoretical context centred on functionality of family systems, and in particular those living with disability. Table 4 provides an overview of family systems theory (Bowen, 1978) and in addition presents multiple theoretical models aligned with the focus of this research. Illustrating the theoretical context of this study, in which family caregiving in the context of feeding, swallowing and mealtime disability is the key area of concern, transparency regarding the theoretical underpinnings of the research aims and objectives, and consistency between the theoretical framework and the data collection methods can be demonstrated. Positioning this study within the relevant theoretical context (in addition to the array of published literature published in the associated area to date, not only fulfils an institutional requirement of scientific research but also serves to build credibility by highlighting the meaningfulness of this research (Adom et al., 2018; Green, 2014).

2.6.1 Grounded theory as an opportunity to build an evidence base

Numerous gaps in the research within the area of third-party disability in MND-induced feeding, swallowing and mealtime impairment, described in section 2.4.4.2 and section 2.5, emphasise the need for generation of theory regarding the psycho-social impact of disability of this nature, and lend themselves well to the use of GT. GT can be used to explore and identify the main concerns of family carers in diverse areas; the complexity of the family carer experience of mealtimes in the context of MND-induced dysphagia is compatible with this. Skeat and Perry (2008) highlight that qualitative methodologies, and specifically GT, may be beneficial to facilitate understanding of the complexity of SLT-related disorders, including the extent of the psycho-social impact of feeding and swallowing impairment, and the personal experiences of individuals who live with communication and swallowing-related disability. Theoretical frameworks to inform SLT practice are currently scarce (Hersh & Armstrong, 2013), and for a profession concerned with communication, interaction and social processes, the absence of theory to guide a social approach to intervention is notable. GT is uniquely positioned to make a valuable contribution to the evidence base by illuminating and explaining the actions and interactions that take place within family units impacted by disability, but can also provide insight into those taking place within clinical settings (Skeat, 2010). Knowledge yielded from GT studies may inform an expanded social approach to the management of feeding, swallowing and mealtime impairment, traditionally dominated by the medical model.

Table 4.

Relevant theoretical context situating the current study

Theory/theoretical model	**Family systems theory, Bowen (1978)**	**Circumplex model of family and marital systems, Olson (2000)**	**Family systems illness model, Rolland (1994)**	**Family adjustment and adaptation response model, Patterson (1988)**
Key focus	Family functioning	Family functioning	Family functioning in chronic disability	Family adjustment
Overview	Describes the family unit as a complex system composed of interrelated and interconnected parts. Asserts that the structure and organisation of a family unit influence family member behaviour. Considers that difficulty experienced by one family member can have an effect on all others	Identifies cohesion, flexibility and communication as central dimensions of operational family systems. Asserts that highly cohesive, flexible and communicative family systems have a tendency towards enhanced functioning and adaptation	Depicts the relationship between an illness and the family system experiencing the illness. Attends to psycho-social aspects of illness and disability, key illness phases and family system variables (e.g., multigenerational patterns of coping and universal belief systems) to understand the extent of the impact of an illness	Describes coping and adaptation by family systems. Illustrates that family systems seek maintenance of balance in functioning by using capabilities (e.g., resources and coping behaviours) when meeting demands and managing stressors
Relevance to the current study	Recognises the importance of the family unit in the experience of illness. Acknowledges the impact of disability at family system level. Validates the social environment as a significant feature of the context of disability. Verifies the importance of family centred care Aligned with the emphasis of this study on investigating third-party feeding, swallowing and mealtime disability as relevant not only in respect of the family carer directly but also important given the	Promotes identification of potential facilitators and barriers to optimal functioning in family systems with respect to relationship cohesion, flexibility and communication Emphasises the importance of the relationship within the care dyad, aligned with this study's focus on care-dyad navigation of MND-induced changes to feeding, swallowing and mealtime experiences (from the perspective of the family carer).	Promotes consideration of demands related to disability within the psycho-social domain. Identifies strengths and vulnerabilities of the family unit as being important parameters in family functioning within the context of chronic illness. Invites consideration of a range of intrinsic and extrinsic factors to coping and adaptation in the context of chronic, potentially changeable illnesses Verifies the use of data collection methods which allow for an in-	Supports analysis of family-based enablers and barriers in coping and adapting to stressors. Encourages attention to periods of adjustment and adaptation within an illness process. Highlights potential opportunities for support of adjustment and prevention of maladjustment within family systems Confirms the relationship between illness presence and the impact on family functioning; fundamental in the current inquiry. Supports

	indirect impact of the experience of family carers on the feeding, swallowing and mealtime experiences of PwMND	Centres the relevance of uncovering opportunities for enhancing and supporting optimal communication in the context of feeding, swallowing and mealtime disability.	depth investigation of family carer experience. Supports the use of methods which are responsive to the unique, nuanced circumstances of participants	identification of family carer needs in the context of feeding, swallowing and mealtime situations and consideration of avenues for healthcare resource provision to reduce disability impact

2.7 Conclusion

Clinical management guidelines for MND advocate family-centred care models within a palliative framework. MND is an illness long recognised as not only profoundly impacting the individual with the diagnosis, but one where family carers experience significant loss and are subjected to psycho-social and psycho-emotional burden. The negative health outcomes family carers of PwMND experience because of the magnitude of the care demands placed upon them, both physical and psychological, are significant.

Following the introduction of the ICF (WHO, 2001), the WHO identified the need for further development of the framework to more comprehensively capture the extent of disability as it impacts third-parties. Further research is required to ensure a conceptualisation of third-party disability in MND that is relevant for both research and clinical purposes. The ICF (WHO, 2001) has to date been scarcely applied in the context of third-party feeding and swallowing disability, and application of the ICF (WHO, 2001) to those with feeding and swallowing disability secondary to MND is absent within the published literature. MND is an illness worthy of careful attention, particularly considering the extent of third-party disability associated with this illness. Many PwMND experience significant disability in both the ability to self-feed and swallow, and require high levels of support from family members to function in these areas. Currently we do not have a comprehensive understanding as to the nature and extent of third-party disability for family carers who support individuals with feeding and swallowing impairments which can occur as a result of MND nor do we have a theoretical framework to guide practice. Studies available in this area typically focus on very specific aspects of the illness (e.g., gastrostomy feeding) and have been primarily concerned with describing responsibility and role changes, including new decision-making roles. Research identifying the impact of feeding and swallowing disability on relationships within the care dyad is an identified gap.

The primary focus of the inquiry presented in this thesis was to address an under-researched area of feeding and swallowing disability in order to uncover potential enablers and disablers in relation to the impact of this disability and begin to build an evidence base. Further exploration is called for in research that can potentially have real-life benefits for family carers directly involved in the management of oropharyngeal dysphagia in MND, and who are tasked with supporting and caring for their family member with feeding and swallowing disability. The study reported in this thesis seeks to understand how family carers negotiate mealtimes following the onset of feeding and swallowing difficulties for PwMND, uncover key processes that explain how family carers engage in mealtimes and present this information in an explanatory, conceptual frameowrk. The objectives of the inquiry include to identify possible challenges encountered by family carers during mealtimes with family members who experience feeding and swallowing difficulties and to identify how informal caring in MND, specifically during mealtimes, impacts family carers' relationships with care-recipients. The next chapter (i.e., the methodology chapter) outlines and explains the methods and procedures undertaken in this study.

SECTION TWO

RESEARCH METHODOLOGY AND METHODS

Chapter Three

Research methodology and methods

3.1 Introduction

This study focuses on developing an in-depth understanding of the mealtime experience from the perspective of family carers of people with MND (PwMND) and generating a clinically applicable conceptual framework to account for the mealtime changes which occur as a result of Motor Neurone Disease (MND). The study foregrounds family carers alone, acknowledging the unique and complex position family carers are in when navigating MND as a terminal illness, and one which impacts not only the person diagnosed but their supporting family unit. This study acknowledges the crucial role family members fulfil as part of the care triad managing the widespread impairments caused by MND. This chapter details the methodology and methods selected as best fit for the purpose of this study, Corbin and Strauss's (2008/2015) grounded theory (GT). This methodology afforded an opportunity to build a clinically relevant conceptual framework accounting for the processes that family carers undergo when presented with MND-induced changes to care-recipient ability to self-feed and swallow. Knowledge obtained from this study is consistent with a responsive care agenda. The ability to positively impact therapeutic relationships and clinical practice through the development of a framework which could be used to inform service planning, service delivery, and further research in this specific area informed the choice of methodology. The following sections outline the procedures used by the researcher to access participants, and to collect, analyse and synthesise the data. The following sections also outline the steps taken by the researcher to ensure quality and rigour.

3.2 Research methodology

3.2.1 Rationale for using qualitative methodology

Qualitative research examines the social, everyday world experienced by individuals through words, stories, and texts (Liamputtong, 2020), and is used to address research questions which are open, those which demand an understanding of the view of research participants and attend to the context within which this view is situated (Creswell, 2013). By contrast, quantitative research studies which involve research questions requiring traditional experimental manipulation and control, and those which can be rendered down to numerical representation, imply facts and assume key variables on which data can be

collected. Qualitative methodologies centre on understanding social communication in context; they are interested in authenticity of interaction and seek to produce answers that are real-world, functionally useful, translational, and work towards social justice agendas (Hersh et al., 2022). Qualitative methods are therefore best placed to unearth complex details about feelings, thought processes, and emotions which are considered difficult to extract or are inaccessible through alternative methods (Corbin & Strauss, 2015). The central focus of this study is to gain an understanding of the experience of feeding and swallowing impairment within the context of the mealtime for family carers of PwMND. The research is novel, given that the emphasis is on developing an explanatory framework for an issue which thus far has received only descriptive attention in the literature. A causal explanation to account for the experience of family carers of PwMND relative to their experience of mealtimes may be possible, although the complexity of this phenomenon renders it unsuitable and inappropriate for control and measurement currently. In this study, understanding the phenomenon at question involved the interrogation of multi-layered, nuanced, and contextually dependent experiences which have previously not been comprehensively addressed. A qualitative methodology was therefore the most appropriate methodological choice.

3.2.2 Research paradigm: Critical realism

This study has been situated within the critical realist perspective because, for the researcher, critical realism not only offered a coherent and intelligible perspective on the world, it also aligned with the aims, objectives and approach of this study. Developed by Bhaskar in the late 1970s, critical realism is a meta-theoretical perspective firmly situated between the perspectives of *empirical realism* and *idealism* (Archer et al., 2016). Critical realism assumes a mind-independent reality aligned with ontological realism in which causal explanation is possible but accepts the hermeneutic belief that knowledge is historically conditioned and communicatively constructed (Wikgren, 2005). The aim of this study, to offer an explanatory account of MND family carer experience in the context of feeding and swallowing disability that is empirically supported, well informed, and has a higher degree of accuracy than any other competing account to approximating and explaining the reality of carers, was compatible with critical realist philosophy.

The psycho-social changes which occur for family carers secondary to the onset of feeding and swallowing disability for PwMND require explanation at multiple levels, including personal, cognitive, discursive and socio-cultural. This depth of explanation is consistent with the deep ontology afforded within critical realist philosophy. Critical realism acknowledges four different modes of reality and asserts that these may exist

independent of their interpretation within the mind (Fleetwood, 2014). The *materially* real refers to physical entities that exist and whose existence occurs independent of their identification. The *ideally* real refers to conceptual entities such as beliefs. The *socially* real refers to purely social entities; these are observed by some (but not necessarily all) individuals. The *artefactually* real refers to an entity which can exist without knowledge that it exists and may be a synthesis of *materially, ideally,* and *socially* real entities. An *artefactually* real entity could relate to a physical entity which takes on additional meaning or purpose, symbolising something greater than the object itself. To illustrate these modes of reality, one could consider gastrostomy tube feeding. The plastic tubing component of the gastrostomy tube could be considered a *materially* real entity. Plastic tubing fashioned specifically for the purpose of providing safe enteral nutrition may be considered as *artefactually* real; not all tubes like this may be identified by every individual as a feeding tube. Some exposure to or knowledge of enteral feeding is required for the experiencer to interpret a feeding tube as such. The belief that a gastrostomy tube may sustain life is an example of an *ideally* real entity, and the experience of gastrostomy tube placement as a catalyst for changing a power dynamic present within a carer – care-recipient dyad is an example of a potential *social* reality.

The focus of this research is on the *social reality* of family carers in the context of feeding and swallowing impairment for individuals with MND. According to critical realism, *social reality* is characterised by stratified entities, relations, and processes (Fleetwood, 2014). The strata represented within critical realism's *social reality* are autonomous (Bhaskar, 2008), and include *empirical*, *actual* and *real* reality (Fletcher, 2017). *Empirical* reality refers to that which is observable and measurable and relates to the experiences and perceptions of subjects. *Actual* reality refers to actual events and actions which happen regardless of whether they are observed; this level of reality may be accessible through interviews inviting reflection. *Real* reality refers to causal mechanisms as well as structures (e.g., rules, conventions, and cultures) that may act to produce *actual* reality. Knowledge relevant to *real* reality must be gained through the processes of abduction, where attempts are made to identify potential antecedents of actions and behaviours, and retroduction, where attempts are made to specify causal mechanisms underlying actions and behaviours (Archer, 1998).

In critical realism, there is an appreciation that multiple levels of reality interact to create an emergent social reality (Wikgren, 2005). The emergent nature of reality means that entities at lower levels (e.g., *empirical reality*) may contribute to reality at another level (e.g., *actual reality*), although, as the higher-level strata are qualitatively different from the lower-level strata, reality at the higher levels cannot be reduced to the entities present at

the lower levels. For example, disability conceptualisation within a society may be considered to be rooted in, although irreducible to, the *materially, artefactually, ideally* and *socially r*eal entities present within that society. In attending to factors such as the presence of and funding available for accessibility supports for use within communities, the extent of disability legislation in place in society and themes present within the social discourse on disability, important inferences about how disability is conceptualised within a society can be made. However, these entities alone cannot be used to comprehensively and completely describe or explain the reality of a society's conceptualisation of disability.

By occupying a critical realist perspective during the current study, the researcher attended to multiple layers of reality, including the *actions* and *events* discussed by family carers in relation to their experience of feeding and swallowing impairment, the descriptions family carers provided in relation to their experiences and beliefs, and/or the processes which could be present and active in the experience of family carers but not overtly discussed (Stutchbury, 2022).

The stratified nature of reality that is presented within the critical realism paradigm supports consideration of the micro-context as well as the macro-context. The unique factors related to the family carers themselves, which may influence the experience of feeding and swallowing difficulties (e.g., previous experience providing care), form the micro-context. The macro-context includes those conditions outside the individual carer which may shape carer reality (e.g., availability of government-funded, professional care supports), knowledge of these conditions is required to gain a comprehensive understanding of the reality of feeding and swallowing impairment for family carers. In critical realism, the characteristics of the individuals under investigation, together with structure-related characteristics (e.g., those that are institution-based), are understood to be the factors which may enable or constrain family carer behaviour, and as such, they are considered to inform reality.

3.2.3 Axiology of critical realism

The capacity to influence the experience of family carers and the behaviours and actions which arise as a result of this experience is afforded via the application of the critical realism paradigm, as interconnectedness of theory and practice is emphasised within the critical realism philosophy. Critical realism assumes an emancipatory value framework concerned with transforming social outcomes through practical action (Easton, 2010), and improving the reality of family carers of PwMND was the key motivation for the researcher in undertaking this study. Critical realism recognises that people have different

perspectives on reality and can effect change because how they act and engage with phenomena shape that reality. For this study, the way family carers experience eating, drinking and mealtime situations shapes how they engage with these situations.

This study brings to light the potentially complex and changeable needs of family carers of PwMND who experience feeding and swallowing difficulties. Knowledge surrounding the needs of carers in this area is required to guide health and social care professionals (HSCPs) who provide services addressing specific feeding and swallowing difficulties in MND. Knowledge of this nature is also required to inform health service planners to ensure that the services provided acknowledge the role of these individuals in the management of MND. Orientating care in this way may enhance the engagement of family carers with HSCPs and subsequently improve the care received by PwMND. By extension, outcomes experienced within the wider family unit may be positively impacted.

To shape outcomes for family carers, recommendations for practice must take account of the structures at work that generate significant events and discourses, and the mechanisms which lead to behavioural tendencies and countertendencies (Bhaskar, 1989). Knowledge obtained in studies framed by critical realism philosophy present tendencies (rather than laws) given the social world is acknowledged as being permanently open. The researcher aligns with a *realist* ontology, believing there are truths and facts about the experience of family carers of PwMND who have self-feeding, swallowing and mealtime difficulties, but asserts an interpretivist epistemology that truths and facts are experienced, interpreted and communicated by individuals with unique histories, backgrounds, perceptions and behavioural predispositions influencing the formation of truth. Truths and facts are therefore considered as patterns, uniformities, or regularities present under certain conditions (Pawson & Tilley, 1997). Situating this study within the critical realism paradigm allowed for sensitivity to several factors which may work together to contribute to the behavioural tendencies and countertendencies of family carers providing support in the context of feeding, swallowing and mealtime difficulties. The development of explanations which are contingent and conditional enables predictions with respect to family carer behaviour (Pawson & Tilley, 1997). Given knowledge and understanding of these processes for family carers of PwMND, guidance relative to clinical practice is possible.

3.3 Research approach

3.3.1 Considering research designs

The researcher's interest in the present case was in how family carers' subjective experiences may be abstracted into a framework useful to guide clinical practice (Suddaby, 2006). Specifically, the aim of this research was to 1) develop an in-depth understanding of the mealtime experience from the perspective of family carers of PwMND and 2) generate a conceptual framework accounting for the mealtime changes that occur as a result of MND. The objectives for this study were 1) to identify possible challenges encountered by family carers during mealtimes with PwMND who experience feeding and swallowing difficulties and 2) to identify how informal caring in MND, specifically during mealtimes, impacts family carers' relationships with care-recipients. The research questions in this study centred around understanding how family carers negotiate mealtimes following the onset of feeding and swallowing difficulties for PwMND and uncovering key processes that explain how family carers of PwMND engage in mealtimes with the family members in receipt of their care.

In attempting to understand the meaning of feeding and swallowing disorders for family carers of PwMND, this study sought to offer direction regarding care provision. Indeed, healthcare policy addressing behaviour can be optimally effective only if that behaviour is understood (Foley & Timonen, 2015). Rather than achieving a *description* of the subjective experience for family carers, as is the end-product of some other qualitative research designs (e.g., qualitative descriptive studies), the researcher desired to *explain* important and potentially complex social patterns, processes, and interactions which occur within family care relationships, situated within the mealtime experience.

The strength of GT in exploring and explaining social action and interaction and in understanding the processes which act to maintain or limit behaviour was considered most beneficial in achieving the aims and objectives of this study. The potential to develop a clinically relevant conceptual framework representing a best fit account of the feeding, swallowing and mealtime experiences for family carers of PwMND was important for the researcher in considering the potential impact of this study (Boychuk Duchscher & Morgan, 2004). The potential application of concepts identified in the developed framework, including important contextual and causal conditions shaping family carer action and interaction, beyond the immediate context of the study, influenced the choice to proceed with GT and subsequently with decisions regarding interviews as the method of data collection. Other methods of data collection (e.g., focus group discussion) were not

considered to be suitable by the researcher given ethical challenges associated with heterogeneity in participant experience. Individual preferences for involvement in topics discussed, in light of the sensitive nature of the potential topics associated with this area of healthcare (e.g., gastrostomy as a life prolonging intervention), required a carefully considered approach to consent, difficult to ensure in group-based discussions. Individual interviews were also considered most beneficial in reducing confidence and social desirability bias that can influence the quality of data in group-based approaches to data collection.

The current absence of theory underpinning clinical practice and informing healthcare policy relevant to third-party disability in this specific area, and the power of a well-developed, conceptual framework to inform clinical practice, future research and policy (a unique feature of GT research), guided the researcher's choice in research design. While it is acknowledged that other approaches to research may have presented valid choices for researchers primarily aiming to inform clinical policy (e.g., Delphi study), the objectives of this study: 1) to identify possible challenges encountered by family carers during mealtimes with PwMND who experience feeding and swallowing difficulties, and 2) to identify how informal caring in MND, specifically during mealtimes, impacts family carers' relationships with care-recipients were centred on explaining social processes. These objectives called for an exploratory research approach that could enable an open, in-depth investigation of the individual-level experience with attention to specific intrinsic and extrinsic factors identified by the participants as relevant to their experience; a unique benefit of individual interviews.

3.3.2 Grounded theory as a family of methods

GT is a commonly used qualitative methodology for health research (Pawluch & Neiterman, 2010) and is defined as a methodology of data collection and analysis which applies a set of methods systematically to generate inductive theory in a substantive area (Glaser, 1992). GT was developed by two social scientists, Barney Glaser and Anselm Strauss, as a method, style and paradigmatic approach to qualitative research. In conceiving GT, Glaser and Strauss provided a framework for collection, coding and analysis of data for use in the development of theoretical explanations of human behaviour built from or "grounded" in the data. GT is particularly useful when no theory exists, as the end-product of GT serves as a foundation on which further research may be developed.

GT aims to develop a formal theory, or theory of substantive scope (substantive theory), to explain human behaviour and, more specifically, the psycho-social processes that underpin this behaviour (Glaser & Strauss, 1967). However, while formal theory development is possible, the more common end-product for GT studies conducted within academic contexts is a conceptual framework given *full* explanation and prediction across all aspects, stages and consequences of a phenomenon is not always possible (Timonen et al., 2018). This will be discussed further in section 3.3.4.1.

3.3.3 Evolution of grounded theory

Since the development of GT, multiple variants of GT methodology have evolved. The evolution of GT into different strands has been debated among grounded theorists who acknowledge the importance of development and improvement, but also caution against changing processes to such an extent that the essence of the original approach is lost (Breckenridge et al., 2012). Denzin (2007) describes multiple forms of GT, including those with positivist, postpositivist, constructivist, objectivist, postmodern and situational roots. However, it is generally accepted that there are three main GT methodologies; Classical GT (Glaser & Strauss, 1967; Glaser, 1978), 'Corbin and Strauss' GT (Strauss & Corbin, 1990, 1998; Corbin & Strauss, 2008, 2015) and Constructivist GT (Charmaz, 2000).

3.3.4 Contrasting Classical, 'Corbin and Strauss', and Constructivist grounded theory

The 'Corbin and Strauss' approach to GT (Corbin & Strauss, 2008/2015) was the preferred approach for this study, and this approach was selected following careful consideration of the nuances of three of the major approaches. The separate methodologies within the GT family emphasise different analytical procedures due to their differing philosophical underpinnings. Despite these differences, similarity remains across many features contained within each variant. A comparison of the main approaches to GT is presented in Table 5. This information represents consensus on the parameters uniting and differentiating the three main approaches within GT methodology. Although variation exists, the core methodological strategies used across all GT variants include concurrent data collection and analysis, constant comparative analysis of data, and theoretical sampling, with the overarching goal across the methodological variants being theory development (Timonen et al., 2018).

Table 5.

Main Approaches to Grounded Theory (adapted from Breckenridge et al., 2012; Charmaz, 2008; Evans, 2013; Kenny & Fourie, 2015; Skeat & Perry, 2008)

Component	Classical Grounded Theory, Glaser & Strauss (1967); Glaser (1978)	Corbin & Strauss Grounded Theory, Strauss & Corbin (1990/1998) Corbin & Strauss (2008/2015)	Constructivist Grounded Theory, Charmaz (2000)
Research paradigm	Positivism/post-positivism; focused on the discovery (emergence) of pre-existing truths and theories	Post-positivism/constructivism	Constructivism; focused on creating and inventing models to explain human behaviour
Ontology	Naïve realism/critical realism	Critical realism	Relativism
Epistemology	Objectivist	Interpretivist	Subjective/interpretivist
GT product	Set of well-integrated conceptual hypotheses, organised around a core category, that fits the situation studied and can be used for further research. The emphasis is on patterns of behaviour to provide a conceptual, rather than descriptive or interpretive, rendering of behaviour	A verified theory of a phenomenon that allows for understanding and management of that problem	An intimate exploration of the meanings participants attribute to their experiences via the researcher's interpretive understanding resulting in a diffuse theoretical product (not centred on a core category)
Research problems and questions	A general problem area is identified before the study; the actual problem and questions emerge from the data	Area of focus and broad research questions are identified before the study; suggested by personal experience, literature and/or colleagues. Research questions are refined during data analysis	Area of focus and research questions are identified before the study; suggested by personal experience, literature and/or colleagues. Research questions are refined during data analysis

Literature review	Literature review is discouraged at the outset of the study to reduce potential influence on the study and ensure an open mind. Once the core category has emerged, literature is used as data, and is incorporated into the theory using constant comparison	Literature is used before the study to suggest sensitising concepts. Literature is used during data analysis to support theory development. The analyst's prior knowledge and experience may and should be employed throughout all stages of the project	Literature is used at every point in the study. However, total immersion in the literature is delayed until the end of the study as it is held that the research is influenced and informed by the context in which the researcher operates
Sampling and data collection	Theoretical sampling techniques are used, guided by emergent research questions suggested by concepts and properties discovered in the data. Sampling is of incidents to compare with other incidents in the emerging theory to develop and saturate categories	Theoretical sampling is used, guided by the emerging theory and analytic questions/hypothesis of the researcher. Specific sampling methods (open, relational/variational, and discriminate) match coding/ analysis phases. Sampling is of incidents, events and happenings to develop and saturate categories	As data is analysed, preliminary concepts and categories begin to emerge. These concepts and categories guide subsequent phases of data collection. Theoretical sampling continues until theoretical saturation is reached
Data analysis	Simultaneous collecting, coding and analysis of data. Constant comparative analysis is required to enable the development of a theory that is credible, consistent and closely related to the data	Simultaneous collecting, coding and analysis of data. Constant comparative analysis is required to enable the development of a theory that is credible, consistent, and closely related to the data	Simultaneous collecting, coding and analysis of data. Constant comparative analysis is required to enable the development of a theory that is credible, consistent and closely related to the data
Coding	Two coding phases are described to *discover* theory; substantive (including open and selective coding) and theoretical Constant comparison is the key analytical tool. Researchers can use a theoretical 'coding family' (e.g., process, strategy) to integrate	Three overlapping coding phases occur: open coding, axial coding and selective coding to *create* theory Coding uses the paradigm model, in which conditions, actions/ interactions and consequences are described for categories in order to show relationships between them. A	At least two coding stages are used: initial or open coding, and refocused coding, in order to *construct* a conceptual interpretation of the data

	categories and frame the theory, or to create their own. Coding memos are used to aid conceptualisation and integration of categories and properties	conditional matrix is used to summarise and integrate the three levels of coding. Memos and diagrams are developed throughout the research process to illustrate evolution of theory development	
Memo writing	Reflecting and deliberating on the data as concepts begin to emerge occurs via memo writing, used to illustrate ideas, facilitate the theorising process and provide an audit trail	Reflecting and deliberating on the data as concepts begin to emerge via memo writing, used to illustrate ideas, facilitate the theorising process and provide an audit trail	Reflecting and deliberating on the data as concepts begin to emerge occurs via memo writing, used to develop comparisons, grow ideas, maintain focus and create a space for engaging with the research process
Means of evaluation	Specific criteria are used to evaluate the theory: fit, work, relevance, and modifiability	Generic qualitative criteria are used in addition to criteria related to the research process (e.g., justification for the original sample) and the empirical grounding of the study (e.g., conceptual density of categories)	Quality criteria including credibility, originality, resonance, and usefulness reflect the research paradigm and emphasise the importance of context

3.3.4.1 Research end-product in grounded theory

Bradbury-Jones et al. (2017) assert that alignment of orientation, technique and innovation in qualitative research holds value in the prevention of "muddling", that is, unnecessary confusion that could otherwise threaten the distinctiveness of a chosen methodology. Indeed, inconsistency or dilution of the research end-product caused by reduced coherence of research technique with the research approach can be understood to reflect on research quality (Creswell, 2013). Typically, when researchers take on GT as a 'full package', they aspire to develop theory. However, as Bryant (2017) identifies, the end-product in GT studies can also include "*models* or *frameworks* or *conceptual schemas*" (p. 99).

Bryant's (2017) point of view may speak to a degree of flexibility afforded in the research end-product across the different approaches to GT, but perhaps also highlights an interchangeability in terminology used by researchers to describe the research end-products arising from GT studies. For the purpose of this study, theory is defined as an abstract, organised and systematic set of interrelated statements (concepts) which specify the nature of the relationship between two or more variables, in order to understand reality with respect to a particular phenomenon (Fain, 2004; Varpio et al., 2020). In GT, this theory is an explanation of how and why people experience and act/interact with events and situations they encounter that has been grounded in qualitative data (Corbin & Holt, 2011). Although it can be argued that GT studies should result in theory development, Timonen et al. (2018) take a different perspective, describing the assertion that a fully elaborated theory must arise from a GT study as a 'myth'. Timonen and colleagues (2018) maintain that "the most common outcome from a GT study is greater conceptual clarity, or a conceptual framework which is short of theory in the sense of a comprehensive set of ideas intended to fully explain or predict something" (p. 4). Of course, as Green (2014) postulates, it may be "a matter of interpretation as to when concepts become organised and interrelated enough to be deemed theories" (p. 35).

In the current study, the researcher aspired to contribute to a theoretical foundation in respect of the area of interest: third-party feeding, swallowing and mealtime disability experienced by family carers of PwMND. She took a pragmatic approach, consistent with Timonen et al. (2018), regarding the nature of the expected end-product of the research. The highly specific nature of the inquiry and predicted homogeneity within participant demographics (e.g., an almost exclusively white-Irish cohort sampled within Ireland) were considered impractical to mitigate given the time and resource limitations associated with this study. These factors were acknowledged by the researcher to impact the scope of this

study and influenced the researcher in setting expectations regarding the research end-product. The researcher predicted multiple challenges limiting the ability to achieve a fully elaborated theory. Therefore, in undertaking this study, the aim was to present a well-contextualised conceptual framework identifying key concepts and categories and explaining the relationship between the categories through adherance to GT procedures (Corbin & Strauss, 2008/2015). The development of an explanatory conceptual framework, defined by Miles et al. (2014) as a visual or written product that "explains either graphically or in narrative form the main things to be studied-the key factors, variables, or constructs-and the presumed relationships among them" (p. 20) was considered an appropriate step towards building theory within the substantive area (i.e., the experience of feeding, swallowing and mealtime disability for family carers more broadly). Being able to offer direction regarding key concepts as well as explanation regarding how the key concepts relate to the phenomena of interest in a conceptual framework, as opposed to attempting to replicate the reality of the experience using main features of influence, as would be the case if presenting a model as the end-product (Passey, 2020), was considered appropriate. Guiding future choices in research procedures, as well as providing a lens for the understanding of the experience of family carers as they navigate MND-induced fading, swallowing and mealtime challenges, useful in clinical practice and to guide policy, were significant impacts expected in undertaking this research.

3.3.5 Rationale for 'Corbin and Strauss' grounded theory

The multiple methodological alternatives within GT offer flexibility to the researcher when situating their study. However, choices in this respect are a documented challenge for novice researchers when deciding which version they will proceed with (Breckenridge et al., 2012). The 'Corbin and Strauss' GT approach (Corbin & Strauss, 2008/2015) was selected for this project as it is aligned with ontological realism; consistent with the researcher's belief that there is one reality for family carers which exists separately from how that reality is experienced, and simultaneously supports the interpretivist epistemological stance, consistent with the researcher's belief that knowledge about reality is constructed. In this case, the researcher's position was that the experiences of family carers could not be investigated in-depth without attending to the unique contexts of the family carers. The 'Corbin and Strauss' GT approach (Corbin & Strauss, 2008/2015) was considered accessible to the researcher, and this together with the cognitive cohesion it presented for the researcher influenced the decision to proceed with this variant. While methodical organisation and structure has been a point of contention

amongst qualitative researchers, and is a criticism of the 'Corbin and Strauss' GT approach (Corbin & Strauss, 2008/2015) (Goulding, 1998), the guidelines provided by Corbin and Strauss (2008/2015) for doing GT were considered advantageous to the researcher who had no experience using the method prior to this study. Compatibilities of 'Corbin and Strauss' GT (Corbin & Strauss, 2008/2015) with the researcher's view regarding the significance of the impact of the researcher on the research process, and her objection to Glaser's assertion of researcher as a 'neutral observer' (relative to potential preconception, prior knowledge and experience, as well as in reference to the potential influence of researcher position on data interpretation), contributed to the decision to proceed with the 'Corbin and Strauss' GT (Corbin & Strauss, 2008/2015) approach. The classic GT principle of *tabula rasa* ("blank slate") did not align with the researcher's beliefs on the role of the researcher. In this study the researcher's background and experience were considered beneficial in enhancing theoretical sensitivity.

3.4 'Corbin and Strauss' grounded theory: Methodological procedures

The end-product in GT provides a relevant foundation for explaining phenomena but also delineates concepts and hypotheses for further research (Corbin & Strauss, 2015). Coding is the primary method of data analysis, and in 'Corbin and Strauss' GT (Corbin & Strauss, 2008/2015), this occurs across three overlapping stages: *open, axial,* and *selective* coding. Uniquely, analysis occurs in tandem with data collection and commences immediately on initiation of data collection.

In the initial stages of coding, researchers are focused on "opening up" the data to identify *concepts* which can then be grouped into *categories*. Corbin and Strauss (2008/2015) suggest a conditional/consequential matrix (adapted in Appendix A) which may be used to attune the researcher to both intrinsic and extrinsic factors active in the carer's experience of a phenomenon (namely *causal conditions* and *contextual factors*), particular actions and interactions which may arise in experience of a phenomenon, and consequences related to the presenting action-interactions, all of which must be present in the data to be considered relevant to the evolving theory (Corbin & Strauss, 2015).

Early categories of grouped concepts are interrogated through theoretical memoing, an analytical process used to explore and document evolving insights on the data (Corbin & Strauss, 2015). Theoretical memoing gives rise to theoretical sampling, where the researcher follows up on theoretical leads suggested in the data. In theoretical sampling, participants who have specific characteristics, or who have experienced specific incidents

and events, may be sampled, interview questions may be steered in a specific theoretical direction, and/or the researcher may return to previously collected data to conduct further analysis with new theoretical perspectives (Conlon et al., 2020). Using theoretical sampling, the researcher aims to confirm categories, saturate the *properties* and *dimensions* of the categories, demarcate the links between the categories, and understand the importance of each of the categories within the structure of the evolving theory/framework. A theory (or, in the case of the findings presented in this thesis, a conceptual framework) involving a set of categories that are systematically developed in terms of their properties and dimensions, and are interrelated through statements of relationship, can ultimately be confirmed as accounting for the phenomenon of interest.

3.5 The role of the researcher

Social phenomena are believed to exist independent of the researcher's interpretations when occupying a critical realism perspective. However, the researcher's linguistic, socio-cultural, and political context are acknowledged to have some bearing on the knowledge gained through the investigative process as the researcher creates meaning based on their own frame of reference (Morse et al., 2002). As stated in section 1.4, the researcher in this study has clinical experience working with PwMND, family carers, and wider family units impacted by MND, as well as other palliative illnesses. She was familiar with the relevant literature in this area, having completed a pilot study (Daly & Jagoe, 2016) prior to embarking on the current project. The research question was formulated at the outset of this study (due to academic institution requirements), and the opportunity to comprehensively address the research question and improve practice was acknowledged as the primary motivation for the researcher in undertaking the research.

In this study, the researcher was the sole individual responsible for the collection, analysis, and interpretation of the data. Decisions made during interviews relative to the lines of inquiry with which to engage, the foregrounding and backgrounding of information presented by the participants within the interviews, and the pursuit of theoretical leads were acts of the researcher within her own linguistic, socio-cultural and political context as well as her clinical background. While bias is typically understood to be a concept aligned with quantitative research paradigms rather than qualitative research paradigms, given the inherently subjective nature of qualitative research (Galdas, 2017), concepts of rigour and trustworthiness, aligned with qualitative research acknowledges the active role of the researcher in the research process. Strategies to manage the potential impact of the personal position of the researcher on the research process (otherwise termed research interpretation bias) including formal reflection on the researcher's role in the research

process, researcher engagement in reflexive journaling, the use of peer review of early interview transcripts and the arising set of codes (considering potential alternative explanations in the analysis of the data), enhance the trustworthiness of research. These strategies were employed by the researcher in this study to remain consistent with the pedagogy of the chosen methodology (Corbin & Strauss, 2008/2015) and optimise rigour. A transparent account of the researcher's process in shaping the generation and analysis of data, and of the efforts taken to examine potential preconceptions, assumptions and prejudices whilst maintaining methodological consistency with 'Corbin and Strauss' GT (Corbin & Strauss, 2008/2015) is provided in section 3.12.

3.6 Research methods

The primary method of data collection used in this study involved individual, semi-structured interviews. The following sections will present the ethical considerations, access, recruitment, data collection and analysis processes, as well as participant demographics.

3.6.1 Ethical approval

Ethical approval was initially sought from the Research Ethics Committee (REC), School of Linguistic, Speech and Communication Sciences at Trinity College Dublin (TCD) prior to undertaking this study. Local ethical approval from the Medical Research Ethics Committee (MREC) at Beaumont Hospital (Dublin) followed. Subsequently, multiple additional RECs across Ireland were contacted, given the project had a nationwide remit and the researcher was endeavouring to maximise access and recruitment, as well as minimise potential local and institutional bias. Amendments to the original ethics documentation were required on multiple occasions. The first amendment was sought in response to access difficulties; this allowed the researcher to recruit via the charity that supports PwMND and their families in Ireland, the Irish Motor Neurone Disease Association (IMNDA). A gatekeeper within the National Centre for ALS/MND at Beaumont Hospital (Dublin) requested the researcher seek an amendment to allow contact to be made with potential participants via post rather than in person; this amendment was sought and approved. Amendments were also required following the onset of the global Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) pandemic to enable data to be collected through virtual platforms rather than in person which was applicable for the final four interviews. Table 6 provides a detailed summary of the contact made with all REC/MRECs including all ethical approvals for the study. Ethics documentation is available on request.

3.6.2 Ethical considerations

Investigation into the experience of serious ill-health is sensitive, given that topics including end-of-life (EoL) decision-making and bereavement are often involved. Strategies to protect participants must be given significant consideration when conducting all forms of healthcare research as it is paramount that ethical principles are upheld. This is particularly relevant when research subjects are defined as “vulnerable”. The concept of *vulnerability* has been discussed in the literature and is typically considered to be multifaceted, complex, and nuanced, as well as subject to variation, given that it is defined in respect of a set of societal values and beliefs which can change (Alexander et al., 2018), whereas the phrase ‘risk of vulnerability’ reflects vulnerability as a function of individual as well as situational characteristics (Fineman, 2008). PwMND and their family carers are considered by research ethics committees to be at a higher at risk of vulnerability to negative consequences which may arise due to participation in research as they directly experience or are living in the context of terminal illness (Alexander et al., 2018). In the current study, protection of participants was foregrounded.

3.6.2.1 The voice of the family carer

The gatekeeping process for safeguarding research participants is paramount because a need exists to protect research participants, particularly those who are at risk of vulnerability. However, in studies involving individuals who are considered to be at risk of vulnerability, a risk has also been identified relative to “paternalism” in gatekeeping (Ewing et al., 2004). Paternalistic behaviours can mean potential participants are not made aware of research projects they would otherwise be suitable for inclusion in when a gatekeeper’s sense of protection becomes overexpressed (Alexander et al., 2018). Bracken-Roche and colleagues (2016) outline that paternalism can occur based on unfounded assumptions and stereotyping and may impact the autonomy of individuals who would otherwise be willing to participate in research studies. Preventing individuals who are considered to be at risk of vulnerability from participating in research can limit the progression of the evidence base, in this case, evidence informing healthcare interventions for family carers of PwMND. Exclusion from research increases the risk that care provided by HSCPs does not consider the realities of the family carer experience, is largely reactive, and insufficiently addresses family carer needs. All risks to research participants are valid and require consideration throughout the research process.

Table 6.

Ethical Approval Processes

Committee	Application type	Submission date	Approval date
Research Ethics Committee, School of Linguistic, Speech and Communication Sciences at TCD	Original	September, 2015	November, 2015 **REC reference MT2 2015/16**
Research Ethics Committee, School of Linguistic, Speech and Communication Sciences at TCD	Amendment-sought to allow use of IMNDA as gatekeepers	January, 2016	January, 2016 **REC reference MT2 2015/16**
Medical Research Ethics Committee (MREC) Beaumont Hospital	Original	November, 2015	August, 2016 **MREC reference 16/29**
Medical Research Ethics Committee (MREC) Beaumont Hospital	Amendment-sought to allow gatekeeper to contact potential participants via post	March, 2017	April, 2017 **MREC reference 16/29**
Ethics Committee, Milford Care Centre, Limerick	Original	February, 2018	February, 2018
Ethics Committee, University of Limerick Hospital Group	Original	February, 2018	February, 2018 **REC reference 031/18**
Ethics Committee, Primary Care Services (Nationwide)	Original	April, 2018	April, 2018
Medical Research Ethics Committee (MREC) Beaumont Hospital	Amendment-sought to allow virtual interviews	June, 2020	September, 2020 **REC reference 16/29**

3.6.2.2 Protection of research participants: Informed consent

In completing the ethical applications for this study key ethical principles were considered, as specific processes around informed consent and protection of research participants were essential. A global assessment of potential risks and benefits for the research participants (Silverman, 2013) was conducted at the outset. Potential research participants who were made aware of this study via the use of gatekeepers were given seven days to consider all information (written and verbal) provided to them before they

agreed to proceed with the interview or with the researcher making contact to further discuss the requirements of the study.

Initial consent to involvement in this study was given verbally by the participants either directly to the gatekeepers and/or the lead researcher and was later verified in writing via a signed hard copy of the consent form (Appendix B), which was provided to the researcher. Steps to ensure participants were aware that their participation was completely voluntary, not linked in any way to care provision, and that they could withdraw consent at any time during the research process were outlined in the participant information leaflet (Appendix C). This information was reiterated by the researcher both before and during data collection. Research participants were made aware that their choice to accept or decline involvement in this study at the outset had no implication for the clinical services they were entitled to receive.

Participant consent warranted careful attention as flexibility was required in the line of interview questioning used during data collection. The exact nature of the questioning undertaken by the researcher during the interviews could not be predetermined at the outset of the research study or prior to each individual interview. The interview questions remained open and dependent on the data from preceding interviews as well as any new directions for theoretical sampling (Corbin & Strauss, 2015) arising. Participants were made aware of the flexible nature of interview questioning prior to their involvement in this study and were reminded by the researcher that they could withdraw consent at any stage during or after the interview process. Participant consent was confirmed online at multiple points during data collection. The researcher acknowledged at the outset of each interview that some of the interview questions arising could prove emotionally sensitive for participants (e.g., questions regarding enteral feeding framed as life-prolonging interventions in MND care; questions regarding risk-taking behaviour in the context of feeding dependency), and participants were informed that they were not obliged to answer any questions they did not wish to.

3.6.2.3 Protection of research participants: Beneficence and non-maleficence

Beneficence and non-maleficence were addressed in the design of this study. Bereaved carers as well as people currently providing care for individuals with (for the most part) a rapidly progressing and terminal illness were involved in the study, and as such, the participants themselves were considered unlikely to benefit directly from the findings of the research. Participants voiced an altruistic commitment to improving service planning, design, and delivery for future family carers of people with feeding and swallowing

difficulties secondary to MND as the primary reason for their participation. The participants also expressed a desire to contribute to the wider portfolio of research on MND in Ireland. The sense of "giving back" was also a motivating factor frequently voiced by participants in respect of their participation in this study.

In-depth interviewing involving self-reflection, reappraisal, and self-disclosure has the potential to negatively impact psychological status and wellbeing (May, 1991; Silverman, 2013). Provisions to mitigate potential psycho-emotional risk were considered vital in this context. Access to psychological support in the event that involvement in this study contributed to any negative psychological outcome for the participants was negotiated through IMNDA. All participants were informed of the availability of psychological supports funded through IMNDA in case their involvement in this study caused any level of distress. The opportunity to access psychology services via IMNDA was reiterated with one participant following data collection. Rather than being associated with any specific event observed during the individual interview itself, this discussion was initiated by the researcher based on her observation of a global level distress experienced by the participant, which appeared to be in response to bereavement. Participant wellbeing was monitored by the researcher throughout all interviews and overtly checked at regular intervals to ensure participants were consenting to proceed within the context of the evolving interview. At times, interviewing paused in response to the researcher's perception of participant affect and level of comfort. All participants remained willing to share their experiences, no individual withdrew consent, and all participants completed their interview in full.

3.6.2.4 Protection of research participants: Confidentiality and anonymity

Protection of research participants involves the researcher upholding conditions to maintain participant confidentiality and anonymity (Lewis, 2003). Individuals in this study were interviewed at a private location of their choosing; for all but one participant, this location was their home. One participant, Fran, chose to be interviewed in a private room in the Department of Clinical Speech and Language Studies, TCD. While not overtly stated, it was the researcher's impression when planning the logistics of this interview that the person with MND whom the participant was providing care to was not aware that this carer was participating in the study.

Information collected and stored by the researcher included a participant information summary which was necessary to arrange the logistics of data collection (Appendix C); consent forms required to ensure informed consent processes were adhered to (Appendix

B); audio-recordings of interviews required to ensure accurate and comprehensive analysis of data; field notes necessary to capture relevant contextual information, including non-verbal information, which may have influenced the analysis of the recorded data; and individual interview transcripts. The processes guiding data storage were compatible with the Data Protection Act (Government of Ireland, 2018) and the standards required of the multiple RECs which approved this study. All data storage was carried out with the verbal and written consent of the participants (Appendix B). Any information that could be used to identify individuals as participants in this study was kept separately and securely from any data collected in a locked filing cabinet. Audio-recordings were deleted immediately following transcription, and these transcriptions contained no identifying information. Informal field notes compiled by the researcher online or immediately after an interview contained no identifying information. The researcher's reflective journal contained no identifying information and direct quotes from participants presented in the findings for this study have been pseudonymised.

3.7 Participant recruitment

3.7.1 Initial sampling

The purpose of this study was to develop an in-depth understanding of feeding, swallowing and mealtime challenges for family carers of PwMND, therefore in this study only the perspectives of family carers were sought. The research question informed participant selection as family carers of people with feeding and swallowing difficulties secondary to MND were targeted in the initial process of purposive sampling (Morse, 2007), this allowed initial identification of contextual factors influencing the experience of family carers. Although theoretical sampling is a requirement of all GT studies, data must be collected and analysed before theoretical sampling is possible (Sbaraini et al., 2011). In the preliminary stages of data collection, purposive sampling was used to access participants who fit the inclusion criteria. It was the researcher's intent to achieve a broad and heterogeneous population in the early stages of sampling. Significant variation in participant characteristics and contextual conditions was considered best to sensitise the researcher to the complexities of the experiences of family carers.

As this study progressed, theoretical sampling was necessary to interrogate the emanating concepts and categories and to comprehensively describe those contexts and causal conditions that appeared to be active in shaping the experience of feeding, swallowing and mealtime difficulties for the participants. An explanation of *how* and *why* specific actions and interactions occurring both within and beyond healthcare settings was possible to obtain through theoretical sampling. Theoretical sampling in this study led the

researcher to sample not only for variation in participant characteristics (e.g., relationship to care-recipient; age) but for critical events (e.g., the onset of feeding dependence) and incidences (e.g., family carer support for the withdrawal from social meals). For example, the nature of the relationship between the members of the care dyad (e.g., whether the participant was a daughter providing care to her mother or a sister providing care to her sister) as well as family carer age (whether the participant was a young or middle-aged adult) was interrogated to assist the researcher in understanding the relevance of the pre-existing power dynamic on how family carers might enact *protection* (e.g., through a choice of strategies such as *strategic communication* and *balance and compromise)*. Specific experiences at critical moments, such as the onset of feeding dependence, were also sampled. Demographic features, although important to sample in some instances in this study, were not the sole basis for sampling. As this study progressed, sampling was most often based on events, incidents, and occurrences which could give insight into the relationship between categories in the framework. This was required to account for the family carer's experience of providing care in the context of feeding, swallowing and mealtime disability, consistent with the chosen methodology (Corbin & Strauss, 2015; Timonen et al., 2018).

3.7.2 Access to participants

Access to participants in this study was initially negotiated through a member of the multidisciplinary team (MDT) providing clinical services within the National Specialist Centre of ALS/MND at Beaumont Hospital (Dublin), who acted as a gatekeeper. Multiple gatekeepers from within the TCD-based Research Motor Neurone (RMN) group were later involved in facilitating access to potential participants. RMN is an organisation with charity status that provides support for MND research. Staff within RMN have the responsibility of maintaining the Irish Motor Neurone Disease Register, which aims to capture data on individuals with MND in Ireland. Every patient diagnosed with MND is encouraged to register on the Irish Motor Neurone Disease Register (Health Information and Quality Authority [HIQA], 2024), which tracks the incidence, prevalence, and clinical features of MND for all individuals in Ireland (HIQA, 2024). RMN were the most active gatekeepers in this study. Research staff based at the National Centre of ALS/MND at Beaumont Hospital (Dublin) as well as staff within IMNDA, assisted with recruitment.

Recruitment was open to all individuals in Ireland. Potential participants were informed of this study verbally via gatekeepers who were in direct contact with family carers of PwMND at the National Centre of ALS/MND at Beaumont Hospital (Dublin) as well as through RMN. Posters displaying the study details (Appendix D) were disseminated via

social media platforms and formal publications (e.g., IMNDA magazine “Connect”) as well as via hard copy displays at the National Centre of ALS/MND at Beaumont Hospital (Dublin). Research posters were sent out to potential participants following ethical approval to do so. Despite the multiple strategies employed, recruitment remained an ongoing but not insurmountable challenge in this study.

3.7.3 Participant selection

Inclusion criteria were used to ensure that participants possessed common characteristics salient to the subject under study, yet maintained a level of diversity within the boundaries of the defined population so that the range of features could be optimised. The inclusion and exclusion criteria for this study are outlined in Table 7. Designated gatekeepers within RMN, IMNDA and the National Centre of ALS/MND at Beaumont Hospital (Dublin) informed individuals who fulfilled the requirements of the inclusion criteria that the study was taking place. Participants self-selected involvement in the study based initially on information provided on the research poster (Appendix D), obtained verbally in discussion with the gatekeepers, presented with the participant information leaflets (Appendix E), or obtained in discussion with the researcher.

The composition, geographic location of the members of the family unit, and the functions a family unit serves may be considered as unique and dynamic. Irish society is recognised as having become increasingly diverse in recent times, and an inclusive definition of the term ‘family’ in this study supported each participant to define ‘family’ based on his or her own personal criteria. The inclusion criteria also required participants to self-determine whether they considered themselves to be carers. Although this criterion may be considered broad, other studies focused on carers in MND have utilised similar criteria (Pagnini et al., 2010; Ray & Street, 2006).

Participants were not excluded from this study if they were bereaved, as during the very late stages of illness it is difficult for family carers to devote time to research that they would otherwise choose to participate in (Addington-Hall, 2002). Indeed, the experience of family carers extending across the full continuum of the carer experience was of interest to the researcher. It was expected at the outset of the study that inclusion criteria would require adjustments in line with the evolution of the conceptual framework in order for the researcher to pursue specific lines of inquiry. However, theoretical sampling in the late stages of this study did not require an adjustment to inclusion criteria given broad inclusion criteria, heterogeneity of participant demographics across key parameters

achieved incidentally, and the emphasis on specific feeding, swallowing and mealtime-related events and incidences required when following up on theoretical leads.

Table 7.

Inclusion/Exclusion Criteria

Inclusion criteria
Participants must be English-speaking and over 18 years old with the capacity to consent
Participants must identify or have previously identified themselves as the family carer of a person with MND
Participants must have observed care-recipients experience change to swallowing and/or feeding function as a result of the onset of MND
Participants must consider themselves well enough to participate in an interview lasting approximately 90 minutes and possibly involving the discussion of sensitive information
Exclusion criteria
Participants with a physical or psychological illness that may preclude their participation in an interview lasting up to 90 minutes and possibly involving the discussion of sensitive information
Participants are known to the researcher

3.7.4 Recruitment activity

Recruitment to this study commenced in January of 2016. Twenty-one participants were involved in the study, with the completion of data collection in October 2020. Table 8 provides specific details of recruitment activity by recruitment centre (with the omission of the centres that were unable to successfully recruit).

Recruitment and attrition are known to be problematic for researchers investigating in the field of MND. MND is not only relatively rare but also fatal and can be associated with a rapid deterioration in function. Family carers of PwMND are heavily time-burdened, particularly as the illness advances and the PwMND becomes increasingly reliant on family carers to assist them in completing activities of everyday life (Jenkinson et al., 2000; Whitehead et al., 2012). Eight participants declined participation in this study following initial consent to be contacted by the researcher. Table 9 provides information on family carers who declined to participate after initially consenting to being contacted by the researcher regarding this study.

Table 8.

Recruitment Activity

Centre	Number of participants consenting to participate	Number of participants who declined participation	Number of participants withdrawn from the study	Total number of participants identified to lead researcher
RMN Register Ireland	13	5	3	21
Beaumont Hospital	6	3	0	9
IMNDA	2	0	0	2
Total	21	8	3	32

At least half of the individuals who consented to being contacted in relation to this study and later declined to participate did so based on time limitations of some form. The number of participants who were contacted by the gatekeepers and declined any further contact or involvement in this study, or those who were aware of the study via social media and chose not to be involved, is unknown. Likewise, the number of individuals the gatekeepers decided not to approach with details of this study is unknown. Three participants were withdrawn from this study by the researcher following initial consent (by the gatekeeper within RMN) as successful contact could not be made.

Table 9.

Reasons for Declining Participation after Gatekeeper Identification (n=8)

Reason	Frequency
Time limitations	3
Multiple studies in progress concurrently	1
No reason provided	4
Total	8

3.7.5 Sample size

The adequacy of the sample in qualitative studies is judged based on both sample composition and size (Vasileiou et al., 2018). According to Sandelowski (1995), qualitative sample sizes should be large enough to allow a 'new and richly textured understanding' but small enough to allow a "deep, case-orientated analysis" (p. 183) of the phenomenon under investigation. Sample size in qualitative research is strongly linked with the concept of data saturation, which may be applied in various ways to a data set. Relative to 'Corbin and Strauss GT', data saturation occurs at the point at which the collection of further data does not yield any new insights or discoveries respective to the issue under investigation or to the story, model, theory, or theoretical framework arising from the analysis (Corbin & Strauss, 2015).

In GT studies, recruitment, data collection and data analysis continue until the study aims are met. Exact numbers of participants cannot be predetermined at the outset of a study; rather, sample sizes in qualitative studies must be data-driven (Corbin & Strauss, 2015). However, in seeking ethical approval for PhD studies, an expected number of participants is often required. The guidelines presented by Creswell (1998) outline that 20 to 30 participants are typically sufficient to reach data saturation in GT studies. Given the specificity of the research question in the particular context of the population under inquiry and in light of prior publications in the field of MND, 20 to 30 participants were expected to be included at the study's outset.

Data sampling in this study continued until the point of theoretical saturation, that being the point at which gathering more data yielded no further theoretical insights about the emerging framework (Charmaz, 2006; Timonen et al., 2018). In the early stages of data analysis, opening coding yielded no new codes after the first six interviews. The boundaries of categories that arose through the advanced stages of data analysis were illuminated and defined at interview number 18, with no further properties of the theoretical categories being revealed during the final three interviews. Morse (2000) suggests that the more useable data there is, the fewer participants are required. The researcher acknowledges that consistent with the limitations of this PhD study, a fully elaborated theory was not possible. However, the development of the conceptual framework presented was achieved with the sample of 21 participants in this study.

3.7.6 Interviews

Participant interviews commenced in January 2016 and ended in October 2020. Twenty-one interviews were conducted by the researcher (i.e., one interview with each participant)

and were completed in full in one sitting. A 90-minute upper limit was set for interview times, as previously published qualitative research involving family carers of PwMND reported interview times not typically extending beyond 90 minutes (Brown, 2003; Gysels et al., 2008; Lisiecka et al., 2020; Olsson Ozanne et al., 2012). Recruitment of family carers who are known to experience significant time burden (Andersen et. al., 2012; Jenkinson et al., 2000; Whitehead et al., 2012) was thought to be maximised with this 90-minute (upper boundary) time commitment. The average length of the interviews in this study was 69 minutes.

Seventeen of the 21 interviews were conducted in person. The remaining four interviews were conducted remotely (owing to SARS-CoV-2 restrictions); two of these were conducted via telephone and two via videoconferencing using the RedZinc Software Company BlueEye virtual clinic platform (Morris et al., 2020). Interviewing via virtual platforms was the standard for conducting qualitative research during this time and presented an option comparable to face-to-face interviewing in respect of the quality of the data yielded (Foley, 2021). A profile of characteristics relevant to the interviews conducted in this study is presented in Table 10.

Table 10.

Interview Characteristics

Characteristic	Descriptive
Interview length	Range: 43 to 113 minutes Mean: 69 minutes
Interview location	Home: face-to-face (16/21) Home: remote (4/21) Department of Clinical Speech and Language Studies, TCD: (1/21)

3.7.7 Sample characteristics

The collated demographic characteristics of the participants of this study are presented in Table 11.

Table 11.

Collated Participant Characteristics (n=21)

Characteristic	Descriptive
Sex	Female: 13/21 Male: 8/21
Ethnicity	Irish (white): 20/21 Non-Irish (white): 1/21
Age at time of interview	Range: 19 to 88 years Mean: 54.90 years
Age caregiver role commenced	Range: 19 to 88 years Mean: 53.57 years
Geographical location[a]	Rural: 14/21 Urban: 7/21
Relationship to care-recipient	Husband: 7/21 Wife: 7/21 Daughter: 5/21 Son: 1/21 Sister: 1/21
Time spent as a carer (self-determined)	Range: 1 to 120 months Mean: 19.76 months
Caring status	Currently providing care: 16/21 Bereaved: 5/21
Living arrangement	Bereaved[b]: 5/21 Lives with PwMND only: 10/21 Lives with PwMND and dependents: 3/21 Does not live with PwMND: 3/21
Employment status	Paid employment: 8/21 Regular unpaid care[c]: 5/21 Retired: 7/21 Student: 1/21

Note. This table presents collated characteristics of the family carers involved in this study.

[a] The term 'urban' refers to participants living in a city within Ireland, and the term 'rural' refers to participants living outside of a city.

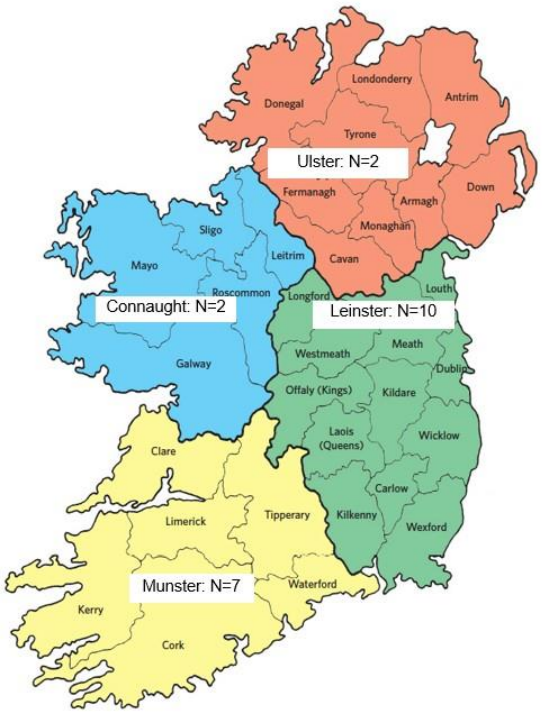
[b] All but one of the bereaved participants resided with the care-recipient when providing care.

[c] Regular unpaid care involved unpaid care provided to the PwMND and/or childcare.

A summary of the geographical spread of the participants involved in this study is presented in Figure 1.

Figure 1.

Map showing participation by province of residence at the time of interview



Note. The provincial location of the participants of this study at the time of interview is depicted in the above image. Adapted from *New Genealogical Atlas of Ireland* (p. 1), by B. Mitchell, 2009, Genealogical Publishing Company, Inc. Copyright 2002 by Genealogical Publishing Company, Inc.

A detailed presentation of the individual participants' profiles is presented in Table 12 for comparative purposes. Relative to employment status, five individuals were identified as being in unpaid employment. Iris and Lisa were undertaking unpaid childcare responsibilities as well as providing care for their family member with MND; Carol and John were on unpaid leave from paid employment as well as providing care for their family member with MND; and Deirdre had not been in paid employment prior to taking on care duties for her husband, who had MND. All but four of the carers (Hallie, Iris, Mike, and Una) had lived (in the instance where the carer was bereaved) or were currently living with the care-recipient. The family carers noted as not (currently) living with or not previously living with (in the case of bereavement) the PwMND had been sharing care duties with other members of the wider family unit as part of an informal care team. Three of these four carers (Iris, Mike, and Una) were living separately and had dependent children.

Table 12.

Individual Participant Characteristics (n=21)

#	Pseudo -name	Age[a]	Sex	Location	Duration of care (months)	Marital status	Living arrangement	Primary employment status [a]	Relationship to PwMND	# of additional dependents [a]	Assistance provided with FEDS [ab]
1	Anthea	27	Female	Urban	20	Single	Bereaved Lived with PwMND	Paid employment	Daughter	Nil	Full
2	Bonnie	67	Female	Rural	18	Married	Lives with PwMND only	Retired	Wife	Nil	Full
3	Carol	53	Female	Urban	4	Single	Lives with PwMND only	Regular unpaid help	Daughter	Nil	Nil Adapted cutlery in place
4	Deirdre	54	Female	Rural	12	Married	Lives with PwMND and a dependent	Regular unpaid help	Wife	1	Nil Adapted cutlery in place
5	Enid	60	Female	Rural	12	Married	Lives with PwMND only	Retired	Wife	Nil	Moderate
6	Fran	53	Male	Rural	120	Married	Lives with PwMND and dependents	Paid employment	Husband	2	Full
7	Gina	83	Female	Urban	15	Married	Lives with PwMND only	Retired	Wife	Nil	Nil
8	Hallie	29	Female	Urban	8	Single	Not living with PwMND	Paid employment	Daughter	Nil	Nil
9	Iris	25	Female	Urban	7	Single	Not living with PwMND Lives with a dependent	Regular unpaid help	Sister	1	Minimal
10	John	54	Male	Rural	9	Married	Lives with PwMND and a dependent	Regular unpaid help	Husband	1	Nil
11	Karen	19	Female	Urban	5	Single	Lives with PwMND only	Student	Daughter	Nil	Nil Adapted cutlery in place

#	Pseudo -name	Age[a]	Sex	Location[c]	Duration of care (months)	Marital status	Living arrangement	Primary employment status[a]	Relationship to PwMND	# of additional dependents[a]	Assistance provided with FEDS [ab]
12	Lisa	73	Female	Urban	3	Married	Lives with PwMND only	Regular unpaid help	Wife	Nil	Nil
13	Mike	39	Male	Rural	24	Married	Not living with PwMND Lives with a dependent	Paid employment	Son	1	Full
14	Nonnie	55	Female	Rural	1	Married	Lives with PwMND only	Paid employment	Wife	Nil	Full
15	Oliver	70	Male	Rural	23	Married	Bereaved Lived with PwMND	Retired	Husband	Nil	Full
16	Peter	88	Male	Rural	3	Married	Lives with PwMND only	Retired	Husband	Nil	Nil
17	Quinn	79	Female	Rural	6	Married	Lives with PwMND only	Retired	Wife	Nil	Nil
18	Rory	45	Male	Rural	62	Married	Lives with PwMND only	Paid employment	Husband	Nil	Nil
19	Steve	70	Male	Rural	12	Married	Bereaved Lived with PwMND only	Retired	Husband	Nil	Full
20	Tony	50	Male	Rural	48	Married	Bereaved Lived with PwMND and dependents	Paid employment	Husband	4	Full
21	Una	60	Female	Rural	5	Married	Bereaved Did not live with PwMND	Paid employment	Daughter	1	Moderate

[a] Denotes data at the time of the interview for current family carers and at the time of care recipient death for bereaved family carers.
[b] Ratings are made based on the parameters outlined in the ALSFRS-R rating scale (Cedarbaum et al., 1999).
[C] The term 'urban' refers to participants living in a city within Ireland, and the term 'rural' refers to participants living outside of a city.

The level of support family carers provided for feeding, eating and drinking differed. Full assistance with eating and drinking was provided by eight of the family carers (Anthea, Bonnie, Fran, Mike, Nonnie, Oliver, Steve and Tony). Of these eight family carers, Fran, Mike, and Oliver were responsible for administering enteral feeds as well as providing oral diet and modified consistency fluids to the care-recipient. Although 12 of the family carers are recorded as providing nil assistance with feeding, eating, drinking and swallowing, or nil assistance whereby adapted cutlery was being used by the PwMND, it should be noted that five of these 12 participants (Carol, Deirdre, Lisa, Quinn and Rory) were shopping, preparing meals in adherence with a modified diet menu, and/or assisting with the set-up of meals to eliminate the need for either on-the-plate diet modification, or assisted feeding.

In two instances (Gina and Hallie) the care-recipient required assistance with enteral feeding only (no assistance was required to support oral intake, including diet and fluid modification, and manipulation of utensils for self-feeding). Of these two, Gina had chosen to delegate percutaneous endoscopic gastrostomy (PEG) feeding support to another member of the family, and Hallie was providing full support with PEG feeds for her family member with MND.

In relation to additional supports used by family carers in the provision of their care, six participants (Deirdre, John, Karen, Lisa, Nonnie and Rory) reported that they did not have additional family members or professional care staff assisting with the physical demands of caring. Three participants (Fran, Peter and Tony) reported that additional family members (only) were available to assist. Seven participants (Bonnie, Carol, Enid, Gina, Hallie, Iris and Steve) reported only having professional care staff available to assist (no family support available), and five participants (Anthea, Mike, Oliver, Quinn and Una) reported having access to both family members, and professional care staff to assist them with the physical demands of caring.

Specific characteristics of the carer's respective care-recipient, considered to be significant in the contextualisation of family carers' experiences and interpretation of the data obtained in this study, are presented in Table 13.

Table 13.

Care-recipient Characteristics

Characteristic	Descriptive
Time post MND diagnosis	Range: 2 to 132 months Mean: 23.48 months
MND type (onset)	Spinal: 11/21 Bulbar: 10/21
MND origin	Sporadic: 20/21 Familial: 1/21
General medical status prior to diagnosis	Nil significant: 16/21 Cerebrovascular illness: 2/21 Psychiatric illness: 2/21 Respiratory illness: 1/21
Diet consistency (Cichero et al., 2017/2020)	Level 7 (Regular): 5/21 Level 6 (Soft and bite-sized) diet: 9/21 Level 5 (Minced/moist) diet: 2/21 Level 4 (Pureed diet): 5/21
Fluid consistency (Cichero et al., 2017/2020)	Level 0 (Thin) drinks: 14/21 Level 1 (Slightly thick) drinks: 3/21 Level 2 (Mildly thick) drinks: 4/21
Nutritionally supplemented intake	Nil: 6/21 Oral supplementation only: 9/21 Enteral supplementation only: 3/21 Oral and enteral supplementation: 3/21
Assistance with oral intake[a]	Nil: 8/21 Nil with aids and appliances in place: 4/21 Minimal: 1/21 Moderate: 2/21 Full: 6/21

[a]Ratings are made based on the parameters outlined in the ALSFRS-R rating scale (Cedarbaum et al., 1999).

No care-recipient in this study was nil per os (NPO). Despite some evidence in the participants' accounts possibly suggestive of care-recipient cognitive decline, none of the participants reported formal diagnosis of a co-existing cognitive impairment.

3.8 Data collection

3.8.1 Interviewing

Individual semi-structured interviews utilising a minimally directive framework of questioning were used to fulfil the aims of the study. The researcher's own background and experience of working with PwMND together with family carers informed the content of an initial interview topic guide (Appendix F). Arthur and Nazroo's (2003) framework provided direction for the initial (pilot) interview design, and Kvale's (1996) quality criteria for interviews was an additional point of reference. The initial interview topic guide was used in a small pilot study (Daly & Jagoe, 2016) conducted prior to the current study. This was not only used to confirm strategies for recruitment and suggest adjustments to inclusion/exclusion criteria but to indicate potential improvements to the interview guide. The usefulness of the semi-structured interview format was verified in the pilot study as it gave participants scope to guide the discussion and did not restrict the flexibility of the researcher to follow up on key incidents and patterns of interest. Minor additions to the interview guide (e.g., including questions seeking participant advice for current family carers) were included following the pilot study to further explore perspective and increase alignment with the research participant's expressed desire to help others.

The preliminary interview schedule for this study (Appendix F) included questions such as "I'd like to invite you to talk about your experience of mealtimes since MND came into your life." These questions aimed at maximising the opportunity for the construction of contextual knowledge, as knowledge and evidence in the framework for this study were deemed to be influenced by contextual, situational, and interactional factors (Mason, 2002). Strategies to achieve breadth and depth of response as outlined by Legard et al., (2003) were utilised during the interviews, thus helping to avoid researcher assumption. Amplificatory probes (e.g., "What made her nice?"), exploratory probes (e.g., "What did that mean for your family?"), and explanatory probes (e.g., "What made it so difficult for you?") assisted in the attainment of a fuller understanding of participants' experiences and were often used because information presented could give rise to alternative interpretations.

Participants were made aware that, given the focus of the study was on carer experience, the presence of the care-recipient was not required during data collection, rather, could serve to limit the exploration of participant experience and perspective. All but two participants in this study were interviewed independently of the recipient of their care. John and Peter expressed a desire to be interviewed with the care-recipient present in the

room. This inevitably impacted the researcher's line of questioning given that the researcher was sensitive to the wellbeing of all individuals present during data collection. Additionally, care-recipient presence more than likely impacted the interviewee's responses. The presence of the care-recipient in these two instances was the stated preference of the participant and the implied preference of the individuals (PwMND) who chose to remain present for the entire interview. The interviewer proceeded with these scheduled interviews despite the presence of the care-recipient as failure to progress at the point of data collection was considered unethical. As the interviews proceeded the researcher attempted to reinforce the importance of the family carer voice by directing the line of questioning to them. Given it was the PwMND's details originally recorded on the MND register, gatekeeper access to family carers initially occurred through the individual diagnosed with MND who had been registered. Detail regarding the PwMND's facilitation or approval of researcher access to their respective caregiver, and whether the contribution of family carers to this study was mediated amongst the family carer - care-recipient dyads prior to the interviews was not collected in this study. This information may have provided an insight beneficial for the interpretation of the findings of this study and could have offered an interesting perspective on family carer engagement in future studies.

3.9 Data recording

3.9.1 Audio-recording equipment

Although the use of audio-recording is debated in classical GT (Glaser & Strauss, 1967; Glaser, 1978), in 'Corbin and Strauss' GT (Corbin & Strauss, 2008/2015) audio-recording is generally accepted. There is an impetus for the researcher to ensure no data is overlooked, misinterpreted, or forgotten throughout the stages of the study; consistent with academic standards. The researcher audio-recorded all interviews in this study using an Olympus DM-450 digital voice recorder, with each participant's written and verbal consent.

3.9.2 Observational field notes

Field notes are defined by Thorpe and Holt (2008) as contemporaneous notes of observations, capturing relevant non-verbal, visual, and contextual information (e.g., "The participant demonstrated awareness of the recording device on a number of occasions"). They are used to enhance the accuracy of the interpretation of audio-recorded data. Field notes were recorded during data collection to supplement the audio-recordings. These

notes were written immediately after each interview and helped contextualise the data for analysis. Information shared by participants, either before recording had commenced or after recording had ceased, provided further context to the carer perspective and this information was recorded in the field notes (and often also in the reflective journal) compiled by the researcher.

3.9.3 Reflexive journal

Although the individual-level connection afforded through qualitative methods is purported to attract researchers to qualitative methodologies (Corbin & Strauss, 2008), this connection can be a source of influence. Researchers cannot be completely objective in their actions, including their observation of social phenomena, and this may give rise to questions regarding research credibility. In attempting to encapsulate the role of the researcher and understand the potential impact of the researcher on collection, analysis, and interpretation of the data, the researcher engaged in reflexivity throughout the study. Personal reflections on data collected from participants, past professional experiences and an overt consideration of how these might relate in influencing the researcher's understanding of participant's experiences were explored in a reflexive journal. In keeping a reflexive journal (an excerpt from which is presented in Appendix G) the researcher aimed to enhance the treatment of the data by remaining transparent regarding the potential for her presence to impact the data. This practice demonstrates methodological consistency with Corbin and Strauss's (2008) position regarding the role of the researcher in GT (Timonen et al., 2018).

3.10 Preparation of data for analysis

3.10.1 Transcription of interviews

Verbatim transcription of data audio-recorded during the interviews was completed as soon as possible after each interview and was based on the protocol for transcription notation suggested by Jefferson (1984). The transcriptions in this study were largely denaturalised with conventions used which were most appropriate to the research question and methodology underpinning this study. The level of detail represented in the transcriptions was considered to be suitable to meet the research aims while remaining readable and meaningful (Bailey, 2008). The transcription conventions used are provided in Appendix H, and this detail has been included with the data extracts presented in the findings chapters for this thesis. Transcripts were checked against audio-recordings in

their entirety on at least two occasions by the researcher prior to the commencement of data analysis. All participants in this study were provided with the opportunity to review interview transcripts; five participants reviewed their transcripts, and no participant suggested changes. Interview data included a total of 24 hours and nine minutes of audio-recording. The computer software programme NVivo was used to facilitate data handling.

3.10.2 Memoing

In GT studies, collected data is analysed together with memos written on the data. In this study, the researcher wrote reflexive memos as described in section 3.9.3 (see Appendix G), methodological memos which helped focus data collection and analysis (see Appendix I), and theoretical memos to advance thinking relevant to the development and refinement of the conceptual framework (Corbin & Strauss, 2008/2015) (see Appendix J). These memos, together with the transcribed interviews (see Appendix K for an example), formed the dataset for analysis.

3.11 Data analysis

In GT, constant comparative analysis, the process of comparing data for similarities and differences that may exist both within a data set (i.e., the transcription) and across the sets of data, is central to theory interrogation and confirmation (Corbin & Strauss, 2008/2015). The distinct stages of coding specific to 'Corbin and Strauss' GT (2008/2015) are outlined in Table 14 and the reader is directed to Appendix L for further detail illustrating the application of these stages in the analysis of data for this study. Despite the distinct stages of coding, the approach to coding in GT is non-linear and these stages overlap.

Table 14.

Stages of Coding (Corbin & Strauss, 2008)

Coding stage	Description
Open	Segments of data are coded with conceptual labels denoting the concepts they represent. Concepts are grouped into corresponding categories, which can be further developed into sub-categories or abstracted into higher categories. The range of properties within each category is demarcated, and the dimensional ranges are scrutinised by the researcher to form a *dimensional continuum*
Axial	Categories are connected through relationships described by the *paradigm model*; causal conditions, context, intervening conditions, action/interactional strategies, and consequences are considered for each category. Overarching categories emerge
Selective	Categories are integrated with higher levels of abstraction and validated against the data obtained. Theoretical sampling is used to ensure the data is conceptually dense and sufficiently contextualised

3.11.1 Open coding

The researcher began open coding following the first interview. Here, the researcher sought to identify from the raw data, relevant concepts in respect of the experiences of family carers which were labelled with a code. Later, these codes were grouped together in the form of categories. Using gerunds (verbs which can also act as nouns) to name the codes enabled the researcher to foreground the psycho-social processes underpinning carers' experience of feeding and swallowing difficulties during the analysis process. A total of 56 codes were used to conceptually label the data from the first interview. These codes represented the concepts that were observed and often repeated in the raw data.

An example of a code identified in the first interview was '*compromising relationships with professional carers to enhance the feeding, eating, drinking and swallowing experience'*. Through subsequent and ongoing analysis, this code was identified as a property of the category '*balance and compromise'.* The category '*balance and compromise'* occurred in the context of carer '*surveillance and judgement of feeding, eating, drinking, and swallowing situations',* a superordinate category (meaning a category with higher explanatory power than other subordinate categories) which was important in explaining the actions and interactions of family carers who provide care for PwMND.

Another example of open coding within the first transcript was with the code '*experiencing tragic loss with the onset of feeding and swallowing difficulties'.* This code was later

modified and became a property of the category '*sadness and loss',* which was subordinate (meaning a category with relatively less explanatory power) to the superordinate category '*bearing, braving and persevering'.* The category '*bearing, braving and persevering'* explained the overall context for family carers' within which their experience of feeding, swallowing and mealtime changes as they provided care to PwMND were situated.

The first six interviews yielded a total of 131 codes on analysis. No new codes representing raw data were identified after analysis of these first six interview transcripts. The initial 131 codes were reviewed by the supervisors of this study who also reviewed the full transcripts for two of the early interviews, Bonnie and Fran. The peer review process used in this study aimed to uncover potential sources of unconscious bias on the part of the researcher during data analysis. As a result of the peer review of interview transcripts together with the arising codes, all codes identified by the researcher were confirmed as appropriate in reflecting the concepts present in the data. At later stages of data analysis (e.g., axial coding), peer review of the evolving framework enabled the researcher to further explore categories, attune to potential conditional and contextual factors not yet considered by the researcher and make choices with respect to the selection of category labels, particularly when suitable options were semantically close (e.g., the selection of *protecting* to describe the main concern of the participants in this study rather than *preserving*).

3.11.2 Axial coding

Axial coding followed on from the initial open coding of the data as the second stage of coding. However, data from the first interview was included in the second stage of coding, as at the outset of data analysis, the researcher had begun to consider how the arising codes related to one another. To develop the conceptual framework in this study, both the paradigm model (Corbin & Strauss, 2015) and the conditional/consequential matrix (Corbin & Strauss, 2008/2015) were applied. The paradigm model provides a structure for coding data which involves consideration of causal conditions, context, intervening conditions, action/interactional strategies, and consequences, which can be used to identify connections between categories (Corbin & Strauss, 2015). The conditional/consequential matrix is a tool used to enhance the researcher's ability to attend to the multiple layers of variable conditions (micro-, macro- and meso-) that may be active in each participant's experience (Corbin & Strauss 2008/2015), therefore warranting exploration in the data set.

The researcher in this study interrogated the initial 131 codes to ascertain what connections existed between the codes. Some connections between the codes were overtly explained by the family carers. An example of this from the first interview (Anthea) was where the code '*following directions around the management of feeding, eating, drinking and swallowing'* was linked to the code '*negotiating feeding, eating, drinking and swallowing behaviours to maximise safety'*. The two codes were identified together on multiple occasions throughout the transcript and were overtly discussed and interconnected in this participant's explanations. The researcher attended to this code, examined its use across the transcript to understand its relevance, and later attended to this code within the accounts of the other participants. The code *'following directions around the management of feeding, eating, drinking and swallowing'*, together with other codes identified as being conceptually related, were grouped together in this process to form the category '*strategic communication'. 'Strategic communication'* represented one strategy consistently engaged in by family carers when assisting PwMND with feeding, swallowing and mealtime difficulties.

Another example of axial coding taken from within the second interview (Bonnie) is where the code '*adjusting mealtime routines because of feeding, eating, drinking and swallowing impairment'* was linked with the code '*separating from the PwMND'.* The code '*separating from the PwMND',* and its relationship to the code '*adjusting mealtime routines because of feeding, eating, drinking and swallowing'* was explored in the theoretical memos of the researcher as the researcher was attempting to organise and confirm categories. Following theoretical sampling, the researcher identified that '*separating from the PwMND*' was a dimension of the property *'prioritisation'. 'Prioritisation'* was confirmed as a property of the category *'balance and compromise'* which was a universal strategy family carers of PwMND in this study used as they *protected* the wider family unit from the impact of feeding, swallowing and mealtime difficulties related to MND.

Additional to this, the researcher questioned whether the code '*separating from the PwMND'* was applicable only to individuals in married care dyads or whether this code was relevant to participants in other types of relationships (e.g., mother – daughter) given the code was first noted in the analysis of the transcript for Bonnie (who was married to the PwMND she provided care for). The researcher sampled family carers in relationships outside traditional married dyads to further understand the applicability of the code '*separating from the PwMND'.*

3.11.3 Selective coding

In the third stage of coding, known in 'Corbin and Strauss' GT (2008/2015) as selective coding, categories continued to be analysed by the researcher and were cross-referenced with data from all previous interviews, together with associated memos and supporting exploratory diagrams.

Ongoing theoretical sorting facilitated a comprehensive description of the categories themselves and yielded information regarding the relationship of one category to another. An example of theoretical sorting in this study involved the delineation of the categories *'communicating strategically'* and *'balance and compromise',* identified as key processes related to the process *'surveillance and judgement'* which occurred in the context of feeding, swallowing and mealtime-related changes. The categories *'communicating strategically'* and *'balance and compromise'* described how family carers enacted *'protection'.* Initially the researcher identified *'balance and compromise'* as a property within the category *'communicating strategically'.* However, *'balance and compromise'* was delineated from *'communicating strategically'* when additional data collection, theoretical memoing and theoretical diagramming confirmed that the explanatory power of this category extended beyond enactment solely in terms of communication (or the choice not to communicate) information regarding feeding, swallowing, and mealtime status with care recipients, family members or HSPCs. The category *'balance and compromise' was identified as a category within the conceptual framework* that related to *'communicating strategically'* but was identified as more broadly relevant in explaining the behaviour of family carers as they provided both physical and emotional support to care recipients with feeding, swallowing and mealtime challenges.

In 'Corbin and Strauss' GT (2008/2015) a core category, that is, the category with the greatest explanatory power, is verified through selective coding (as well as theoretical sorting) in the advanced stages of data analysis. In this study, a potential core category had been identified in the early stages of data analysis – this was the category '*maintaining dignity'.* Following extensive data collection, theoretical sampling to the point of theoretical saturation, advanced coding, and memoing with the support of explanatory diagrams, the category *'maintaining dignity'* was renamed '*protecting dignity'.* This category later gave rise to a the superordinate category *'protecting'* as the category with the highest degree of explanatory power (i.e., the core category). *'Protecting dignity'* was confirmed as a property of the subordinate category *'protecting the care-recipient'*.

Concepts associated with '*protecting'* had been identified in the early analysis of data (during open coding) and had been coded in multiple ways to reflect the variation of this

concept in the data. For example, the code '*protecting the PwMND from burden'* was often used to represent family carers' reluctance to involve PwMND in providing emotional support to them as they began to accept the impact of feeding and swallowing-related complications they were experiencing. This code was later grouped with the code *'protection of care-recipient psycho-emotional status'* as part of the category '*protection of the care recipient'*.

Another early code that gave rise to the ultimate core category *protecting* was '*protecting dignity in the face of feeding, eating, drinking and swallowing changes'*. This code represented specific actions and interactions undertaken by family carers following the onset of negative sequelae such as care-recipient feeding dependence. *Protecting* was ultimately identified as the core category in this study as it was fundamental to framing and explaining the experience of feeding, swallowing and mealtime difficulties for family carers of PwMND.

3.11.3.1 Theoretical sensitivity

Theoretical sensitivity is required in GT studies in order to support the development of theory as relationships between categories that fit, work and are relevant to the field under investigation are identified (Glaser, 1978). Strategies such as the purposeful distancing of researchers from technical literature or personal experiences which could otherwise lead to forcing of the data into preconceived frameworks consistent with conventional ways of thinking, as well as using a range of analytical procedures that encourage abstract thinking (e.g., constant comparative analysis, looking for the negative case), support theoretical sensitivity (Corbin & Strauss, 2015). Theoretical sensitivity requires reflexivity regarding researcher positionality and an openness to possibilities within the data and is demonstrated in both data collection and analysis procedures (Glaser, 1978).

In order to demonstrate the process of theoretical sensitivity in this study an example is taken regarding the categories *hope*, *protection,* and *gatekeeping.* In this study it became apparent that family carers considered HSCP behaviour with respect to hope and the maintenance of hope within the care dyad. On the basis of the data provided by participants the researcher was sensitised towards perceptions regarding HSCP behaviours which could potentially preserve or violate family carer hope. Data collection (e.g., via theoretical sampling) and subsequent data analysis verified a relationship between *hope* and *protection*. HSCP behaviour which influenced hope tended to influence family carer choices regarding their engagement with HSCPs and their engagement with recommendations arising from HSCP interactions in the management of feeding, swallowing and mealtime challenges. Family carers in this way were identified as being

engaged in a process of *gatekeeping*. Analysis recognised a relationship between HSCP interactions with family carers and the preservation of family carer hope, as well as on the future behaviours of family carers supporting care recipients with feeding, swallowing and mealtime difficulties. The relationships between the categories *hope, protection,* and *gatekeeping* were interrogated in theoretical memos and theoretical sampling to further explore these relationships and guide the developing conceptual framework.

3.12 Ensuring research quality

To ensure rigour in this study, Lincoln and Guba's (1985/2005) criteria for evaluating qualitative research provided an initial point of consultation. Corbin and Strauss' (2015) indicators for quality specific to GT research (see Appendix M) were also integrated within the study design to achieve robustness. The strategies documented in Table 15 were used by the researcher to optimise the integrity of the research and are consistent with both sets of quality standards.

3.13 Conclusion

This GT study sought to explore the perspectives of family carers of PwMND in relation to the feeding, swallowing and mealtime difficulties experienced. This chapter emphasised the relevance of the GT approach to enable the development of a conceptual framework that highlights the key parameters of the experience of family carers and accounts for variation in the experiences of individual family carers. This research is the first GT study in this area attempting to understand the complexity of this phenomenon, therefore this study offers implications for healthcare practice change as well as areas for extending research of similar agenda.

Specific attention was given in this chapter to research ethics and participant recruitment. Despite multiple sampling strategies aiming to capture a nation-wide sample, recruitment remained the single biggest obstacle for this study. The empowerment of family carers of individuals with palliative illness to participate in research has been discussed, not only to highlight the crucial role of these individuals in supporting interventions in palliative care but also to reinforce the importance of gatekeepers in facilitating family carer involvement in research. This chapter has outlined the theoretical underpinnings of the approach used by the researcher to address the research aims. The researcher's ontological and epistemological beliefs and perspective on her role as an active participant in all aspects of this study have been described. The methods involved in data collection, management and analysis in this study are consistent with those outlined by Corbin and Strauss (2008/2015), and these have been presented transparently in this chapter. The systematic

and comprehensive application of the processes required to optimise the rigour and robustness of this research have been explained. This study's findings constitute a conceptual framework depicting key processes involved in family carers' experiences of feeding and swallowing impairment in the context of MND. The findings are presented in the following three chapters, an overview of which is provided at the beginning of section three.

Table 15.

Strategies to Maximise Research Quality (Corbin & Strauss, 2015; Lincoln & Guba, 1985/2005)

Criterion	Strategies used by the researcher	Evidence
Credibility Confidence in the 'truth' of the findings; the researcher provides an accurate representation of the participant's constructions	Adopted the GT approach as best fit to address the aims, objectives, and research questions of this study	Section 3.3
	Maintained sensitivity to the development of rapport from the outset of data collection; utilising interview strategies to maximise honesty	Section 3.6.2.2
	Used a flexible interview guide to ensure the interview was participant led	Appendix F
	Incorporated iterative questioning strategies in interview process to optimise understanding	Section 3.8.1
	Comprehensively and completely transcribed interviews (with information from field notes) and reviewed each transcript at least twice against raw data to confirm accuracy	Section 3.10.1
	Used peer debriefing to assist in uncovering researcher bias during the analytical process, including code checking	Section 3.11.1
	Sought respondent validation of interview transcriptions	Section 3.10.1
	Used self-awareness strategies (including reflexive memoing) to refute assumptions against data	Section 3.9.3
	Searched for deviant cases which did not fit the evolving conceptual framework	Section 3.11.3
	Used theoretical memoing and diagramming as a method of providing an audit trail for the research findings	Section 3.10.2
	Declared the background, qualifications, training, and experience of the researcher; outlined potential sources of researcher bias, and documented strategies to address these	Section 1.4/ Section 3.5
Dependability Confidence that the findings, interpretations, and conclusions for the study are consistent, repeatable, and supported by the data	Maintained methodological consistency within the chosen GT approach (Corbin & Strauss, 2008/2015)	Chapter 3
	Transcribed the interviews in full to ensure completeness of the data set	Section 3.10.1
	Used constant comparative methods of analysis consistent with the GT approach (Corbin & Strauss, 2008/2015)	Section 3.11
	Included all cases in data analysis to ensure data treatment was comprehensive	Section 3.7.7
	Searched for deviant cases which did not fit the evolving conceptual framework	Section 3.11.3
	Continued data collection and analysis (including theoretical sampling) until theoretical saturation was achieved	Section 3.11.3/

	Presented in-depth methodological description (e.g., audit-trail) demonstrating methodological awareness in decision-making Reported the findings for this study in a manner that constitutes fair presentation	Appendix N Section 3.11 Chapter 4/5/6
Transferability Application of the findings in other contexts	Presented sufficient information relevant to participant profile and context for comparative purposes Identified a core category which is sufficiently broad so that it can be used to study other populations and similar situations beyond the current context Weaved conditions and consequences into analysis of data to explain the impact they have Developed a conceptual framework which incorporated processes to demonstrate how the theory may vary under different conditions and be applied to different situations	Section 3.7.7 Section 3.11.3/ Chapter 5 Section 3.11.2 Chapter 4/5/6/ Figure 2
Confirmability Ensure findings are derived from the data	Clearly stated the aims, objectives, and research questions in the presentation of this research Declared the background, qualifications, and experience of the researcher Provided a transparent account of the philosophical underpinnings of this study Ensured an in-depth methodological description (e.g., audit-trail) was provided to demonstrate methodological awareness in decision-making Outlined the rationale behind the processes used for recruitment and sampling; provided detailed methodological description Provided evidence of theory evolution through theoretical as well as reflexive memoing in an audit-trail Engaged in regular reflexive journaling, documenting personal responses to information gathered, and explored non-grounded ideas and personal biases through personal self-reflection Utilised peer debriefing to promote a balanced view of the data collected	Section 1.3 Section 1.4/ Section 3.5 Section 3.2 Section 3.11 Section 3.7 Section 3.11 Section 3.9.3 Section 3.11.1
Authenticity A balanced view of stakeholders' perspectives is apparent	Reported the findings of this study in a manner that constitutes fair presentation of each participant's perspectives Used participant's own words (where possible) in presenting the conceptual framework for this study	Chapter 4/5/6 Chapter 4/5/6

SECTION THREE

RESEARCH FINDINGS

Overview of research findings

This study aimed to develop an in-depth understanding of the mealtime experience from the perspective of family carers of people with Motor Neurone Disease (PwMND) and to generate a conceptual framework to account for the mealtime experiences of family carers in the presence of Motor Neurone Disease (MND)-induced feeding, swallowing and mealtime disability. A heavily contextualised, conceptual framework specifying the universal concern of family carers (i.e., '*protecting')* and identifying key processes that underpin family carer negotiation of mealtimes is presented in Figure 2.

Figure 2.

The conceptual framework representing the feeding, swallowing and mealtime experience of family carers of people with MND

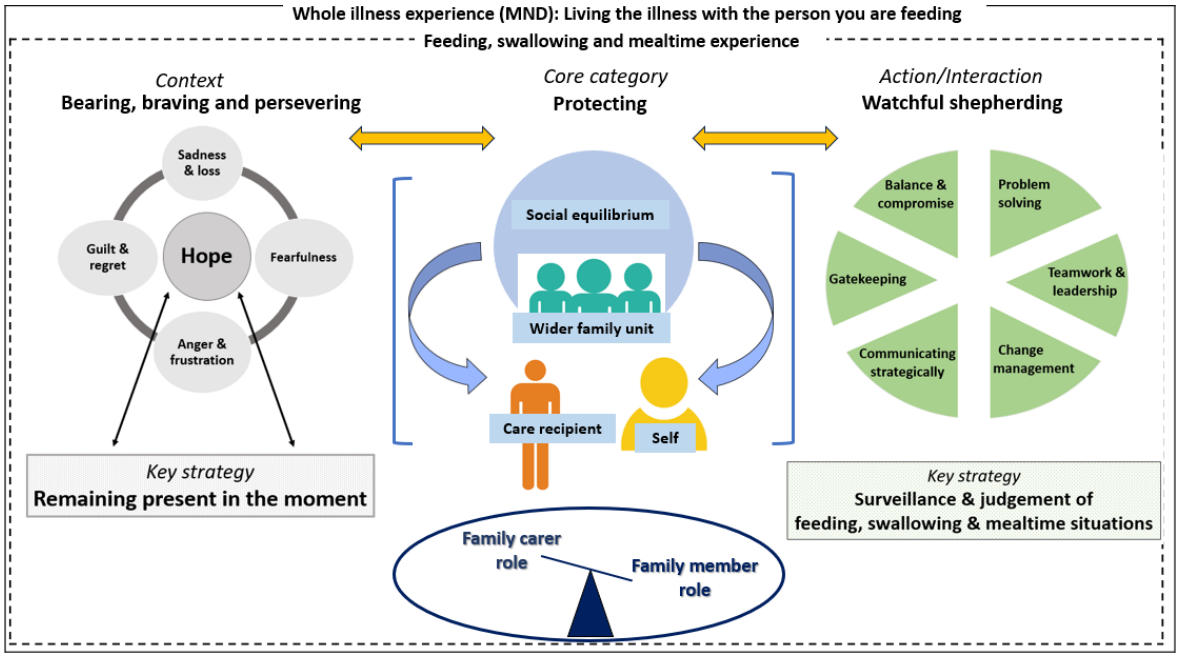


Figure 2 displays graphically the three distinct but interrelated components of the conceptual framework which were grounded in the data for this study: 1) contextual factors, 2) the core category, and 3) key action and interactions of family carers in their navigation of mealtime experiences. Each of the three components is systematically addressed in the three chapters which follow.

The conceptual framework illustrates both key concepts (categories) which describe the mealtime experiences of family carers and additionally depicts the relationship between these concepts (categories). Facilitators and obstacles encountered by the participants in this study within mealtime situations have been identified. These factors, together with

important micro- (intrinsic) and macro- (extrinsic) causal, contextual, and conditional factors shaping the mealtime experience for family carers are described throughout the following three chapters. An awareness of causal, contextual and conditional factors impacting the experience of family carers as depicted in the conceptual framework supports prediction relative to the behavioural tendencies of family carers when experiencing MND-induced feeding, swallowing and mealtime challenges.

This study's findings presented in chapters four, five and six provide a narrative account relevant to the conceptual framework. Extracts of data supporting the interpretation of the findings for this study are provided. The first of the findings chapters is chapter four. This chapter discusses the psycho-emotional landscape of family carers, outlining key psycho-emotional processes the participants in this study identified as crucial in supporting an understanding of the core concerns of family carers in their experience of feeding, swallowing and mealtime challenges associated with MND. Fundamentally, family carers reported having to '*live the illness'* with the care-recipient. This process required '*bearing, braving and persevering'* in the context of feeding, swallowing and mealtime-related challenges. Although the wider illness experience was not the central focus of this study, the experience of the wider illness universally influenced family carer experience of feeding, swallowing and mealtime disability, given mechanisms applicable for coping with the illness (e.g., '*remaining present in the moment'*) were identified by family carers as essential for coping with and adapting to feeding, swallowing and mealtime challenges. An understanding of negative psycho-emotional sequelae caused by the presence of feeding, swallowing and mealtime disability (e.g., '*sadness and loss', 'fearfulness', 'anger and frustration', 'guilt and regret')* was identified by participants as highly relevant in framing the context within which feeding, swallowing and mealtime experiences were situated. This context was paramount given the psycho-emotional landscape of family carers altered the orientation of their assumed responsibility to *'protect'* not only care-recipients but members of the wider family unit and themselves in the context of feeding, swallowing and mealtime-related challenges. The *'unpredictability, uncertainty and lack of control'* family carers experienced over feeding, swallowing and mealtime disability called for family flexibility to *'learn in the moment'.* Family carer *'hope',* optimised through the ability to *'remain present in the moment'* was significant in participant's ability to *'bear, brave and persevere'* while *'facing downwards'* as the feeding, swallowing and mealtime status of the care recipient inevitably deteriorated. The positioning of family carers not only as family members sharing the experience of mealtimes but as individuals with a new responsibility to support the feeding, swallowing and mealtime function of the PwMND required a consolidation of roles, which presented numerous psycho-social challenges to the integrity

of the relationship between, as well as the identities of the individuals within the care dyad.

'Protecting', as has been mentioned, was uncovered as the essential, most powerful explanatory concept that universally underpinned the action and interactions of family carers as they experienced mealtime challenges associated with MND. Chapter five describes *'protecting'* as the core category reflecting the main concern shared by family carers in the context of feeding, swallowing and mealtime changes associated with the presence of MND. Data in this study identified that the action and interactions of family carers could not be understood without understanding the underpinning urge of family carers to *'protect'*. Family carer *'protection'* was most often directed towards care recipients. However, this study illuminated conditions influencing the orientation of protection away from a primary focus on the care recipient, toward members of the wider family unit in an attempt to maintain *'social equilibrium'* when mealtime normalcy was threatened by the presence of feeding, swallowing, and mealtime disability. Evidence in chapter five supports the finding that although infrequent, family carers may seek to self-protect in the context of feeding, swallowing and mealtime challenges when the challenges they experience negatively impact their ability to cope and adapt (i.e., '*bear, brave and persevere'*) and when their ability to continue to provide care at a safe and acceptable standard is threatened. Specific threats which require *'protecting'* against are categorised as either physical, psycho-emotional or psycho-social involving relationships and identities within the care dyad. This study demonstrated that family carers initiate or orientate '*protecting'* via ongoing *'surveillance and judgement of feeding, swallowing and mealtime events and situations'* occupying the role of a '*watchful shepherd'* in doing so.

The concept of the *'watchful shepherd'* is discussed in chapter six, which emphasises the six strategies family carers in this study used to operationalise *'protecting'* in the context of feeding, swallowing and mealtime experiences. Chapter six directly addresses the research question in uncovering the key processes family carers in this study used to engage with mealtimes in the presence of MND. The key strategies used by family carers as they negotiated mealtimes with care recipients in this study included problem solving, balance and compromise, gatekeeping, strategic communication, change management and teamwork and leadership. Care-recipient, wider family unit and health and social care professional (HSCP) support were essential to optimise the effectiveness of the strategies used by family carers to navigate feeding, swallowing and mealtime situations. The choice in strategies used by family carers was made through overt as well as covert *'surveillance and judgement of eating, drinking and mealtime situations'*. Family carers desire to remain

watchful was identified as ever present for family carers who attempted to guide care recipients as care recipients coped with and adapted to the feeding, swallowing and mealtime challenges they faced. Family carer watchfulness and guidance in respect of feeding, swallowing and mealtime situations was administered tentatively by family carers, as this process made the relationship and power changes occurring within the care dyad in the context of feeding, swallowing and mealtime disability overt. Relationship and identity changes forced by feeding and swallowing disability were identified as being more or less challenging under numerous conditions. The personality and temperament of both members of the care dyad, the traditional styles of communication within the care dyad, and the traditional power differential amongst the members of the care dyad are examples of factors which were uncovered as potentially influencing family carer's ability to navigate MND-forced changes to feeding, swallowing and mealtimes. Further discussion explaining this will be presented in the chapters that follow.

Chapter Four

Bearing, braving and persevering: The context of feeding, swallowing and mealtime challenges for family carers

"I remember sitting inside and I thought 'This is way too hard. Now this is a step beyond what I can do.' And then I had to pull my big girl pants up and say 'Feck it, you have to do it.'" (Enid, Passage 208)

4.1 Introduction: Living the illness with the person you are feeding

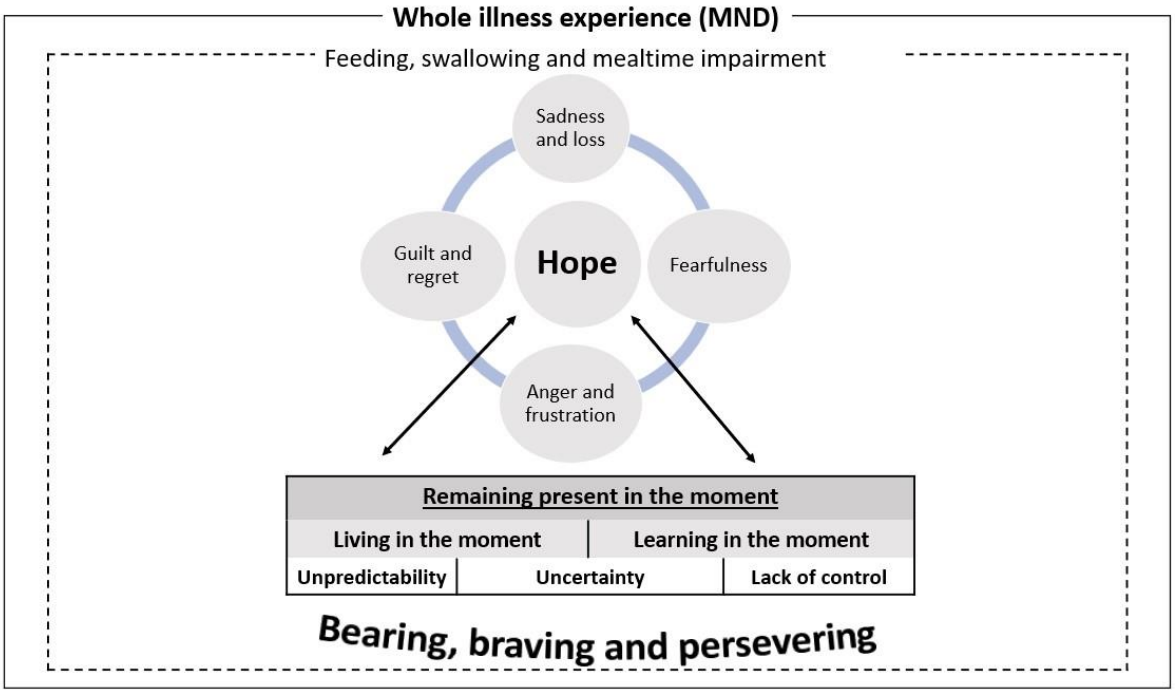
In this study, all participants contextualised their experience of feeding, swallowing and mealtime challenges within their experience of broader illness-related changes. Participants universally reported "living the illness" with the person they were feeding. Participants spoke of the sadness and loss, fearfulness, anger and frustration, guilt and regret they experienced as family members in the unique position of providing the informal care required to support care recipients with feeding, swallowing and mealtime challenges. The psycho-emotional consequences of feeding, swallowing and mealtime difficulties were consistently reported as being inseparable from the psycho-emotional consequences of MND in its totality. However, participants provided in-depth explanations regarding specific changes to feeding and swallowing situations they experienced which contribute to this context. The psycho-emotional consequences for participants in this study were magnified by an illness trajectory which forced them to provide care in an unpredictable, uncertain, and uncontrollable context, and one which could not offer a sense of stability as the disease and the illness-associated feeding, swallowing and mealtime difficulties progressed. In this study, each participant approached their role as a family carer from a unique position and with an individualised set of beliefs, experiences, resources and demands. Although the conditions and context of the participants varied, family carers attempted to remain present in the moment to prevent or diminish potential threats to their sense of hope. The maintenance of hope was central to the family carers' ability to cope with the entry of MND into their lives and with the feeding, swallowing and mealtime disability.

Given its pervasive nature, this chapter presents the psycho-emotional landscape within which the participants in this study situated the experience of feeding and swallowing disability secondary to MND. Figure 3 illustrates key components of the psycho-emotional context of the participants in this study. This figure demonstrates the universal psycho-emotional context of family carers and enables situation of the main concern as well as the operationalisation processes family carers use to navigate the changes to feeding,

swallowing and mealtimes induced by MND. The documented components both relate to, and are influenced by, one another in contributing to the experience of feeding and swallowing difficulties for family carers of people with MND (PwMND).

Figure 3.

The psycho-emotional context of family carers of people with MND-induced feeding, swallowing and mealtime difficulty



Concordant with the detail in Figure 3, this chapter explores the context within which the mealtime experience of family carers is situated, characterised by a process of *bearing, braving and persevering*, related to the properties: 1) sadness and loss, 2) fearfulness, 3) anger and frustration, 4) guilt and regret, and 5) hope. The enveloping sense of *unpredictability, uncertainty, and lack of control* for family carers in the context of feeding, swallowing and mealtime disability and the importance of *remaining present in the moment,* achieved by family carers through 1) living in the moment and 2) learning in the moment, are explained. Data extracts are presented to support the findings, these include transcription conventions, and the reader is directed to Appendix H for the full list of conventions used. The vital nature of the family carer's ability to *remain present in the moment* and the dominant impact of the successful application of this strategy on family carer hope are presented. The impact of hope on the family carer's ability to *bear, brave and persevere* through the MND-induced feeding, swallowing and mealtime changes is evidenced.

4.2 Facing downwards but not giving up: Supporting feeding, swallowing and mealtime disability in the context of palliative illness

4.2.1 Subsuming sadness and ongoing loss

Extensive sadness and loss associated with the onset of self-feeding and swallowing impairment was described by all participants in this study. When the care-recipient's illness was of spinal onset and their upper limbs were involved in the early illness presentation, changes to the care-recipient's ability to manipulate and sustain grip of utensils, necessary for meal preparation and efficient self-feeding, arose. In these circumstances participants were required to support care-recipients early on. In some cases, care-recipients were reliant on adapted or modified cutlery, glasses, cups and plates for them to be able to continue independent feeding despite disease associated physical weakness. The introduction of adaptations and, in some cases, their firm establishment within shared mealtime routines evoked feelings of sadness for family carers who often considered these modifications to be substandard or unacceptable:

> "I hate…-I didn't like using things like plastics to eat stuff because to me eating something out of plastic (…)"… "It doesn't taste the same, I don't know for whatever reason I just don't think it tastes the same."…"I'm just thinking 'You can't enjoy your food as much having it from a plastic spoon and a plastic plate.' It's kind of downgrading it." (Bonnie, Passage 184/188/192)

The messiness of care-recipient eating prior to their request for, or acceptance of, assistance with feeding was challenging for some participants, indicative of the profile of disease-related impairment and a loss of the sense of mealtime normalcy:

> "He (care-recipient) has to lean forward and just let things drip out of his mouth." (Karen, Passage 2)

The care-recipient's inability to tolerate a full range of diet and fluids when swallowing difficulties impacted safety and efficiency of intake was also an important dimension in the sense of loss for participants. The change to their family member's swallow function provided evidence that forced family carers to acknowledge the progression of MND, foregrounding the ongoing presence of this palliative illness:

> "It (swallow deterioration) was just another confirmation that my Mum (care-recipient) did have Motor Neurone Disease. It was just another (…) another seal on it or another nail on the coffin. That's exactly what it was like, another nail on the coffin." (Anthea, Passage 162)

Restrictions in choices for food and fluids arose for some carer – care-recipient dyads given the presence of family member oropharyngeal dysphagia:

> "There would be things you would like to make but you might fancy yourself but you would be saying 'I can't make that because she (care-recipient) can't eat it.'" (Carol, Passage 96)

Witnessing care-recipient inability to tolerate a full choice of meal items was challenging for participants who described the impact when care-recipients were unable to participate in a full range of "normal" mealtime routines previously shared with the carer and the wider family unit, and representing a source of pleasure:

> "I think that at that point I realised that this is huge and that (…) my Mam (care-recipient) can't do what she has always done. Eating is such a huge thing and MND just takes over everything."… "I felt sad that it (red wine) was her actual pleasure. The little things that she enjoyed has been taken away from her. And that's hard because you want for the time that she has left to enjoy. And it's little things like that that she always loved, that she can't anymore. So that's hard." (Hallie, Passage 90/102)

Among other rituals described by participants, the significance of events such as Sunday dinners, family barbeques, celebratory meals, and enjoying a glass of red wine were recognised for the potential to impact both the care-recipient's quality of life (QoL) and sense of self. Not only that, but the ability to maintain food and drink-related routines and rituals provided reassurance to members of the wider family unit who were either involved in or witness to these routines, that the ability of the PwMND and the wider family unit (continuing to undertake these routines and rituals) was uninterrupted by MND. In many cases, where food and drink-related rituals were interrupted, so was the business of family life:

> "It (eating and drinking) is going to be difficult and it is going to be <u>fundamentally</u> life changing from that perspective. Those routines which <u>are</u> the routines that family life are built around, <u>they</u> are the things that get changed and impacted." (Fran, Passage 244)

> "Our norm would be in the morning about half nine, ten o'clock for breakfast and the conversation would start and we might be there for another hour. We can't do that anymore." (Peter, Passage 2)

While limitations in food and drink choices were perceived by many family carers as critically important to the care-recipient's ability to maintain QoL and sense of self, often

the ability for care-recipients to maintain longstanding food and drink-related routines and rituals provided reassurance to family carers that all was well:

> "Well she (care-recipient) even now she still makes the dinner, I let her. We don't fuss about it. If I'm there and I can be a help, I'll do it." (John, Passage 36)

> "There's an attachment. Well I suppose I think it's just food in general. Because he (care-recipient) (…) he would have loved food. Some people don't like food but he loved, he loves it. Funnily enough now he still has his oysters. He always liked, he can still have, which is amazing you know. As awkward as they are to turn and put them in. Yeah, yeah. He'd still have the odd oyster."…" I always thought it was kind of random that he was that big into oysters ((laughing)) and that he would seek them out like. When we would go out then and he would be looking for them and we would always laugh about stuff like that." (Mike, Passage 120/122)

Participants often reported that when care-recipients became unable to tolerate a full range of food and drinks, family carers would also self-impose limitations in the range of food and drinks they would take. Reduced time and resources available to support multiple menu choices and the natural preference for family carers to eat the same meal as their family members were important considerations in these decisions:

> "We were no longer having a meal together. And that was (…) that was a bit difficult (…). But it's like everything, you just get over it again (…). So now it's fine. I get stuff that I like and I have that, and I get stuff that I know he (care recipient) likes and he will have that. But once you get over it, it's not a big deal, it's just a thing. It was just this thing about cooking a meal and eating together." (Bonnie, Passage 63)

The loss of spontaneity and flexibility at mealtimes was reported across the participants who were providing care to care-recipients with self-feeding and swallowing difficulties. This loss was reported to co-occur with a shift in the experience of mealtimes from an enjoyable occasion to a chore:

> "I don't enjoy food anymore. And that's something that I've noticed (…). I really don't. It's completely different now for me." (Hallie, Passage 36)

Not only was there a new requirement for diet and fluid modification at home (a task supported by family carers), but as the care-recipient's ability to eat and drink safely and

comfortably outside the home was impacted, family carers experienced limitations in relation to their ability to go out in public for meals:

> "We were in a situation where we were going out twice, three times a week for a meal. We can't do that now." (Peter, Passage 40)

The withdrawal of care-recipients from eating and drinking outside the home contributed to limitations in the family carer's ability to eat and drink outside the home, given most participants sought to avoid leaving care-recipients during meals. In the case of married care dyads, a sense of separation for participants arose if they engaged in social eating outside the home without the care-recipient:

> "I wouldn't go (to a family celebratory meal) without him (care-recipient) because he would be left here on his own and there is no point in doing that. No way." (Gina, Passage 114)

> "Social engagement is just restricted. So (…) any events I'm there on my own, she's (care-recipient) no longer with me so (…) a lot of enjoyment goes out of that." (Fran, Passage 114)

The loss of involvement in celebratory occasions was commonly reported among participants caring for family members whose feeding and swallowing difficulties seemed insurmountable to their ability to remain engaged in eating and drinking outside the home. There were instances in the data where celebrations were ignored by care-recipients but where participants were able to continue to remain involved. Often family carer involvement occurred with the expressed intent of maintaining routines and rituals, important for a sense of normalcy within the wider family unit:

> "Anything I'm going to is going to be time limited and I'm planning around that. But I'm <u>also</u> conscious that I'm going to a family celebration without her (care-recipient) and I'm leaving her right. So <u>Christmas Day</u> or Stephen's Day the next day, she will be on her own in the house for several hours. And part of that is that we need to <u>stay socially involved</u> right. The children <u>need</u> that as well, the children need to be taken out of all of that and they need to celebrate Christmas right and go there." (Fran, Passage 116)

Participants reported many instances where they modified their own diet and changed their own intake in line with the changes required for the care-recipient. Not only did the participants adjust their intake to avoid a sense of separation, but this adjustment was made by family carers due to the time and resource demands inherent in preparing different meals:

> "I think one of the key things as well, more recently that it suddenly dawned on me is that we don't have to eat the same thing. And I think that was key. And that again didn't dawn on me. And I'm not saying that I (…) that I wasn't enjoying my food because I was but I was thinking what can I do that he's (care-recipient) going to enjoy that. That's because his breadth of types of food have narrowed down now." (Bonnie, Passage 60)

Family carers reported that they would regularly consume modified consistency food despite openly acknowledging that this food was less appetising, and often had been fortified to increase calorific content:

> "I mean if Mark (care-recipient) is having mashed potato with milk and butter I'm not going to have a separate potato for myself. So you have to be practical about it." (Deirdre, Passage 26)

Unavoidable sadness and tragic loss were identified by participants as being associated with the onset of feeding dependence. The loss of the care-recipient's ability to self-feed was consistently highlighted as a critical time point in the illness progression for family carers involved in supporting feeding:

> "It was tragic (…) It was nearly like feeding a baby."…"You'd be feeding her (care-recipient) and (…) she was just so vulnerable (…) she just was like a little sparrow." (Anthea, Passage 144/148)

> "I remember he (care-recipient) was struggling a bit with it so he would just eat some and then he would stop because he just couldn't. So then I would just sit with him and 'Would I give you it?' And he would say 'Yeah, okay.' And then I remember (…) thinking- it mightn't have probably been at that moment, but I remember at some point thinking this could be an issue (feeding assistance) or would be an issue. I imagine that it would be an issue for people, a <u>huge</u> issue." (Bonnie, Passage 78)

Family carers reported being sorrowful that their family member had been "reduced" to dependent living. Family carers were saddened to witness care-recipient embarrassment relative to the level of difficulty experienced with self-feeding as the illness progressed:

> "I suppose seeing someone as close as your Father just the inability to feed himself you know (…) ((becoming tearful))." (Mike, Passage 14)

Feeding dependence was perceived by family carers as disruptive to the flow of the meal and a catalyst for the eventual re-conceptualisation of the meal as a "task" or "chore", given the care needs attached:

> "Mealtime changes for everyone. Mealtime has changed for me. So I can no longer sit and enjoy a meal or could no longer in that scenario because I'm also trying to feed her (care-recipient) and look after her." (Fran, Passage 136)

> "I was sad about it and having to do it (assist with feeding) and she (care-recipient) wasn't able to do it herself. I used to say to her 'Go on, try, try. Try. Try and do it yourself.' But she just wasn't able to do it. She wasn't able to lift her hand high enough to put it in her mouth. No." (Steve, Passage 46)

The establishment of gastrostomy tube feeding was a critical point for the experience of intense sadness and loss. Typically, participants described abandonment of the mealtime by the point of gastrostomy feeding establishment. This abandonment was forced by the progression of upper limb and/or swallowing difficulties beyond the resources available for family carers to continue to support care-recipient oral intake. The abandonment of mealtimes was made easier through the availability of an alternative means of feeding:

> "Up until he (care-recipient) got the RIG (radiographically inserted gastrostomy) he would have come out here (during mealtimes) every day." (Mike, Passage 28)

> "She (care-recipient) has tried your typical Sunday lunch or dinner. She would have tried to stay at the table but that's strange because everyone is eating but she's not eating and she is not part of the conversation (…)."… "Now it's about doing something different, special, and separate for Connie and that happens at a time separate from when we are eating. So a mealtime now becomes a separate, special event. It's an extra part of the day. Feeding Con." (Fran, Passage 134/212)

Some family carers correlated gastrostomy insertion with a rapid deterioration in the health of the care-recipient:

> "After he (care-recipient) come home from having the RIG he seemed to go downhill quite dramatically. We thought that was…-he was on the way out." (Mike, Passage 68)

At times, family carers expressed apprehension regarding potential changes to the self-feeding and swallowing ability of the care-recipient in the future. This could exacerbate sadness for the care-recipient, and subsequently for themselves:

> "She (care-recipient) would wipe like that (demonstrating wiping of her chin) she would wipe herself but she has never made a comment on it and I have never seen her when she was eating be upset with it. And it doesn't upset me, no. She has never really been upset about it. I think when she gets upset about things I would probably be a little bit upset. Because I feel bad for her, I just feel bad that this is upsetting her now, things are starting to come in, that would be upsetting. I would be upset watching her upset." (Iris, Passage 106)

4.2.2 Fearfulness: From apprehension to terror

For many participants caring for family members with bulbar-onset MND, fear associated with swallowing difficulties preceded formal diagnosis and care tasks associated with swallowing and mealtime management (e.g. symptom surveillance) were initiated prior to formal diagnosis. In the context of feeding and swallowing difficulties, fear was largely centred around the potential onset of swallowing difficulties and uncertainty regarding how feeding and swallowing difficulties would progress:

> "It really is up to Sile (care-recipient) to do her best to tell us and tell the medical team, to tell everybody when she starts to have these difficulties (in swallowing) so we can intervene as soon as possible and know what's the best way to go about it." (Iris, Passage 150)

For carers not residing with the recipient of their care, a sense of fear or disquiet was expressed in relation to the new onset of feeding and swallowing difficulties and the level of transparency within the care dyad in relation to potential changes:

> "I feel she's (care-recipient) not really being one hundred percent honest (about the level of swallowing difficulty experienced) and not really asking people to help her. Something dangerous could happen and she is not really thinking about that." (Iris, Passage 162)

For those participants who were not immediately faced with choking as a consequence of swallowing difficulties, most had considered the probability of choking events in the future and were fearful:

> "I do feel anxious that something is going to go down the wrong way." (Bonnie, Passage 92)

> "What frightens me if he (care-recipient) starts choking. But I have the alarm there if he started to. But if he started to, that's…-I'd be afraid of that. I know if I press

> the button I have friends around the corner. I don't like when I'm on my own. You know what I mean? What are you supposed to do?" (Lisa, Passage 212)
>
> "He (care-recipient) coughed and coughed and I thought his lungs were coming out of him one night because he coughed so much. And I thought the sounds he was making trying to get the stuff up, I thought 'Is this what is ahead?' And I was conscious that there will be a time where you know the swallow may be an issue and I just have to stay calm and say 'You'll be fine Ian, you'll be fine.'" (Enid, Passage 230)

Participants who provided care for family members who were experiencing obvious difficulty swallowing were constantly confronted by the fear that the care-recipient would choke. This was particularly intense when the family carer had been present during a previous choking episode:

> "It is difficult when there is a lot of coughing and choking going on. We are quite fortunate that during the week there is only the two of us living in the house so I just suck it up. It's very voluminous. There could be a lot of choking going on. I've asked him (care-recipient) if he wants me to intervene and he will either just shakes his head and we will just work through it and stay sitting until it passes."… "I mean I'm waiting for the day. I could be in a situation where I don't really know how to (…) clear his airways." (Nonnie, Passage 2/38)

Feelings of helplessness arose for participants who reported they felt there was nothing they could do to prevent choking or help when choking episodes occurred:

> "You feel a bit useless and helpless (witnessing choking)." (Carol, Passage 170)

Some participants expressed anxiety and fear, as well as reduced confidence, in relation to how well they were managing the care-recipient's feeding and swallowing difficulties. This included how effectively family carers were modifying diet, assisting with oral feeding, and administering gastrostomy tube feeding:

> "I was a little bit worried about that (choking) because I thought I hadn't, I didn't minced it up completely." (Bonnie, Passage 96)
>
> "I had huge concerns over…-to feed Niamh (care-recipient) you had…-I developed a routine, I was using a spoon, the food would be on the spoon and the first thing I would do was almost push her mouth open, push down on her lower teeth to get her mouth open and then get the spoon in as fast as I could. Often times her

mouth would clamp and the spoon would get caught in her mouth and I would be afraid we would break a tooth." (Tony, Passage 72)

"I was afraid to do it initially but then I got into a routine (of gastrostomy feeding)." (Oliver, Passage 42)

Family carers sense of fear surrounding the ability to manage complications associated with feeding and swallowing difficulties was expressed in this study. Care-recipient preferences for feeding, eating and drinking, including their adherence to recommended diet and fluid modifications and strategies to maximise safety during eating and drinking, were not always aligned with the preferences of the participants. When these situations termed "moral dilemmas" or "internal conflicts" arose, they were emotionally challenging for family carers, as often they included behaviours perceived to have the potential to acutely threaten care-recipient safety. Apprehension arose for family carers when they considered that it was their role and responsibility to protect both the safety and the QoL of the care-recipient, and when these two goals were in direct conflict:

"She (care-recipient) would ask for food and the things that she would ask for it wasn't safe basically. Because she would ask for liquids, pure liquids, and we on one hand really wanted to give her food and give her calories but on the other we knew my Mum had just taken a diazepam and she was a bit (…) a bit more relaxed and we...-it would be better if we were feeding her when she was fully alert. But we did do it and it was something…-it was like dealing with someone who was tipsy or a child you'd be saying 'No, could you do this...-could you eat something else or could we give you a thickened liquid or…'" (Anthea, Passage 58)

Accessing support from family members who were also providing care for the PwMND was beneficial for family carers in overcoming fear and apprehension in the circumstances outlined in the above passage (Anthea, Passage 58). Family carers' access to other family members assisting with care enabled the family carer to share responsibility, receive reassurance and gain support, which were reported by many participants to be protective against fear and apprehension:

"I think I may have spoke to my Aunt about simply acknowledging the fact that I was spoon-feeding her (care-recipient). And that she was spoon-feeding her, just at the start I was saying 'Are you doing this?' and she was saying 'Yes, I'm doing that too." (Anthea, Passage 294)

The availability of additional support via access to healthcare professionals (HCPs) in primary, secondary, and tertiary care services, including general practitioners (GP), consultant neurology and specialist palliative care staff, staff from the Irish Motor Neurone Disease Association (IMNDA), and a full range of health and social care professionals (HSCPs), was often identified as an additional facilitator in the alleviation of feeding and swallowing-related fear and apprehension. Input from formal healthcare agencies was acknowledged by many family carers as a valuable resource:

> "At the time I was getting support from the hospice, so I was able to talk to the experts in there as well (regarding gastrostomy insertion) so they helped and that's what helped. But there was no moving Niamh (care-recipient) really." (Tony, Passage 74)

> "They (IMNDA) are the best people to know. They deal specifically with Motor Neurones. I know a lot of people need intervention with mealtimes but it might not be to the scale of what Motor Neurones is. They can direct me to where would be the best place to get any training or to find out all the information so I'll definitely be getting in touch with them. I want to go to the best people that deal with this and can really show you. If you learn about something you are only learning a general way of it, where we need to learn the Motor Neurone way of it. I suppose checking the muscles and how will they close so 'Will we really have to really puree her foods? When will that be?' Maybe other people might not have the answers for but the Motor Neurone Society have dealt with this with so many patients and they really know." (Iris, Passage 144)

4.2.3 Encountering anger and frustration

Anger and frustration were reported to have been experienced by the participants of this study in response to the impact of the illness on the self-feeding and swallowing abilities of the care-recipient:

> "I would have got times of anger. Not…-it was anger at the disease and what it has done. We will say it might have been a day where it might have been particularly difficult for Niamh (care-recipient) to eat something, and that happened. There were some days where it was difficult and some days where it wasn't. It was strange that way. I would get so angry at 'Why this disease is doing this? Why are we at this? Why?'" (Tony, Passage 42)

Some participants expressed frustration associated with a sense of inadequacy when they believed they were insufficiently meeting the feeding, swallowing and mealtime-related needs of the care-recipient:

> "It (assisted feeding) is very demanding and frustrating when you don't understand what she (care-recipient) needs."… "She can give up. And you as a carer know she has given up because she can't do what she wants to do. So she is annoyed, frustrated and then you are frustrated and as a carer you think 'I've done something wrong here.'" (Fran, Passage 86/120)

On occasion, participants expressed frustration with care-recipients due to their lack of openness regarding aspects of their feeding, swallowing and mealtime impairment. Poor communication of illness-related changes the care-recipients were experiencing amongst professional care staff and with family carers themselves was a source of frustration. It could be distressing for participants when they perceived care-recipients were not being honest about their eating and drinking status:

> "I mean she's (care-recipient) telling everyone she's had this, yeah she's had it but she wasn't <u>eating</u> it. And she was in denial, that was it. She was in denial." (Oliver, Passage 14)

> "He (care-recipient) was even telling some doctor 'Yeah sure I put everything in the slow cooker'. I couldn't tell you the last time I saw the slow cooker out."… "He's adamant that he is fine. But I can see now changes (to swallow function) and I think he knows there's changes but he's just so stubborn that he doesn't want to engage in the fact that there are changes. If that's how he deals with it good for him but that's not how I deal with it. I have to be realistic because I need this to sink in, I need to understand this. I don't need to barely deal with it and then something happens and afterwards thinking I could have done this and this and this." (Karen, Passage 74/170)

The lack of care-recipient transparency reported by participants at times caused disquiet for family carers who then felt unable to openly discuss their own experience of the care-recipient's feeding, swallowing and mealtime challenges. Participants often reported that the ability to discuss the status of care-recipients was necessary in order to be able to access appropriate assistance to help them provide care. A sense of sadness was identified for some participants who were unable to access a full range of supports given care-recipient preferences for care. These instances appeared to be missed opportunities for participants to enhance the care they provided and subsequently impacted family carers experience of third-party feeding, swallowing and mealtime disability.

When care-recipients were perceived by family carers to have a reduced ability to accept illness-forced changes in self-feeding and swallowing which were associated with MND and had a tendency to rely more heavily on the family carer as a result, feelings of frustration could arise:

> "She (care-recipient) would specify what she wanted done (to prepare food) and you would have to do it that way, even if you didn't agree with it." (Anthea, Passage 190)

Increased care demands on family carers when care-recipients were unable to accept aids, appliances and modifications aimed at supporting their independent function could result in frustration for family carers. This was more common when family carer resources were minimal and care demands were chronic and cumulative. Any additional care needed in these circumstances could be overwhelming:

> "Every step of the way was a battle. I don't need that and I don't need that." (Oliver, Passage 20)

When care-recipients had accepted aids, appliances and supports, but given an inevitable deterioration in feeding and swallowing function, these strategies were only effective for a brief period of time, family carer frustration could result. Many participants described frustration in the context of the cyclical process of supporting care-recipient acceptance of new aids, appliances, modifications, and strategies to support feeding, swallowing and mealtime function followed by functional loss:

> "With the Motor Neurone it feels like you are constantly facing downwards. So if they have worked something out on a Thursday (to assist with independent feeding) and I get back on the Tuesday whatever they worked out doesn't work anymore. Constantly." (Una, Passage 60)

> "We found a new thing (adapted cutlery) worked and then unfortunately they would have been useful for a month and then she (care-recipient) wasn't able to use it. The drawers are full of these things." (Fran, Passage 236)

> "A month ago you might be able to fill the spoon three quarters and now you can't. Or you would have to put the spoon to the front left side of the mouth or the right side of the mouth."…"You just have to have the patience and they just have to understand that what worked one day mightn't work today, and that it changes like that." (Tony, Passage 120/128)

For some family carers who had begun to feel confident with their ability to modify diet and fluids, a subsequent change in care-recipient preference or feeding and swalowing status could induce frustration given that carers were required to consider new ways of preparing or administering nutrition, hydration, and medication. Increased care demands contributed to this sense of frustration when increased planning, flexibility and new skill acquisition were required.

4.2.3.1 Anger, frustration and the family carer – healthcare professional interface

The interface of informal carers with professional caregivers could present a source of frustration for family carers as they supported care-recipients with feeding, swallowing and mealtime difficulty. Participants expressed overwhelm at the degree of involvement of HSCPs and the presence of HSCPs at their home, particularly in the immediate period post diagnosis. The presence of HSCPs impacted the privacy of family carers and, for many, felt like an "annoyance" or "intrusion" that would "never end":

> "You feel like you are being swallowed by so many people coming to see him (care-recipient) and how's he doing. You get a bit iffy about it."… "Every day the door was being knocked on and someone wanted to come in and discuss his condition (including feeding and swallowing status) you know. I thought it would keep going for the rest of his life. But as we found out now, it's quietened down. I thought it was going to last forever." (Gina, Passage 148/158)

> "They just kept ringing all the time, and we just kept saying 'Come, come, come.' Hand over fist coming. I didn't ask any questions, we didn't know if it was right or wrong, good or bad. I'm sure I know in the course it was good for James (care-recipient), it was of no benefit to me. It was of no benefit. I learnt nothing." (Nonnie, Passage 244)

Participants described incidents of care that contributed to feelings of anger and frustration based on the timing of HSCP interventions (too early or too late), the degree of HSCP input offered and provided (too much or too little), and the timing, quality, pitch, and amount of illness-related information provided to care dyads. Carers consistently described the sense of overwhelm they felt when large volumes of information relevant to their family members' diagnosis of MND were given by HSCPs at one time. This included information regarding feeding, swallowing and gastrostomy tube feeding:

> "We got all that information in one day. The breathing would be the next thing after the swallow. After getting the tube in probably the breathing would give her (care-recipient) bother. Which was a lot to take in in one go." (John, Passage 65)

Family carers considered both the care-recipients and their own time to be very valuable. When family carers were required to duplicate confirmed preferences for care (including those relevant in the context of feeding and swallowing impairment) amongst multiple members of the formal care team or for new team members, this became a source of frustration:

> "There was duplication, there was crossed wires all those types of things." (Anthea, Passage 214)

> "By the time I learnt someone's name she was gone on maternity leave and then there was another one. Who she was with, I wouldn't have been able to tell you. I really wouldn't have, you know." (Nonnie, Passage 244-extended)

Changes in formal care staffing were frustrating for family carers who were dealing with relentless illness-related changes. Staffing changes could happen without warning, and at these times of change, family carers could be faced with additional threats to privacy. This was particularly apparent for care dyads who were residing in rural settings where it was more likely that they could be familiar with potential professional carers through community-based social activities.

When staff changes occurred, family carer apprehension could also arise regarding the quality of replacement carers. Family carers felt obliged to invest time and energy into training formal carers on the individual requirements of the care-recipient when staff changed. The nature of feeding and swallowing impairment meant that this could involve a significant amount of detail. A sense of abandonment in these circumstances was not uncommon in the reports of family carers, intensifying the sense of burden in the experience of all aspects of care, including that associated with providing feeding, swallowing and mealtime support:

> "There has been far from consistency around carers. The reason she (care-recipient) ended up in respite that week was because the previous care provider had pulled out of the service with no notice because there had been difficulty getting carers and there had been a period of <u>constant</u> change." (Fran, Passage 82)

Anger and frustration relative to the interactions of HSCPs, on behalf of both the care-recipient and the family carers themselves, arose for participants when they felt care provided was formulaic in nature, not considerate of the individual needs of the family unit, and responsive (largely) to demands, requirements and restrictions arising at an organisational level:

> "Well at the time it was frustrating. I remember Con (care-recipient) going to the bother, in the hospital, of going to the bother of travelling into for an appointment with the speech and language therapist to be told that yoghurt would be a good idea (…) And that putting powder in water was a good idea. We just never… -I couldn't relate to that at the time. And I know Con didn't find that particularly helpful."… "That they didn't have better solutions (…) And the assumption was going to be that that was what she would be reduced to. And she never has."… "It set an expectation that things were going to get bad really quickly and it never did. And that wasn't helpful."… "I certainly got the impression that she didn't find that useful. I think she found those appointments, there were only a handful of them, but I think she found them ↑difficult."… "Maybe a generalisation or something. Far too early and far…-and part of that was that we should feel lucky that we were getting an appointment." (Fran, Passage 186-194)

Proactive introduction of diet and fluid modifications, including the use of fluid thickening agents and modified cutlery, and decision-making regarding gastrostomy feeding, were the main sources of pre-emptive care described by participants in this study. Pre-emptive care in the context of the feeding and swallowing difficulties in MND often evoked family carer anger and frustration which shaped the experience of feeding, swallowing and mealtime difficulties:

> "That's probably what becomes unhelpful advice. It I can eat this today then I'm going to eat it today because that's what I would normally do. Tell me I shouldn't be eating it well (…) But if I can eat it, I should be eating it." (Fran, Passage 232)

The progressive nature of MND and the associated feeding and swallowing disability meant that once a functional ability was lost, it would not be recovered.

4.2.4 Mitigating current and future guilt, and avoiding regret

Situations evoking guilt and subsequent regret for family carers were commonly described by participants in this study. Guilt in relation to the quality of care that participants were able to provide for their family members with feeding, swallowing and mealtime difficulty was outlined on multiple occasions and was particularly apparent for carers with high care demands and high levels of fatigue:

> "Maybe at times I would have tried being more patient in dealing with it. In dealing with the situation because I would have got annoyed. At times when I was dealing

with my Mum (care-recipient) we would have fought, which was really difficult." (Anthea, Passage 370)

Family carers experienced guilt when they felt they were unable to meet the care needs of care-recipients which were necessary to optimise safety, efficiency and comfort when eating and drinking. When family carers felt that they required the support of HSCPs to provide care at a level that was acceptable to them, but the preference of the care-recipient was that HSCPs were not involved in care, discomfort arose for participants as they felt they were not able to provide optimal care:

> "She (care-recipient) said it, she wrote when she was able to write 'You know I would do the same for you (provide home-based care without outside assistance).'" (Oliver, Passage 42-extended)

Participants expressed guilt in relation to the actions they undertook during mealtimes while they were supporting care-recipients with feeding and swallowing difficulties. Family carers often regretted the level of encouragement they had given the care-recipient regarding the amount of intake consumed as well as the level of encouragement they had provided care-recipients to maintain care-recipient participation in social meals both inside and outside the home:

> "I'd love her (care-recipient) to (engage in meals outside the home) but she just won't. There's no point. I probably should have challenged her on it years ago." (Fran, Passage 20)

Guilt in relation to the takeover of mealtime-associated roles and responsibilities that had traditionally been those of care-recipients but that were no longer possible for the care-recipients given illness-related difficulties, was expressed by a number of the participants. Family carer takeover of menu planning and meal preparation, assisting young dependent children with their eating and drinking, and providing the predominant source of parental connection with children during family mealtimes were guilt-invoking situations participants reported having to navigate:

> "It means that the conversation which is important in the family just isn't happening. Because Con (care-recipient) may be present but she just isn't engaging in the conversation so one thing she can't do is eat and talk for instance. For a long, long time effectively those conversations at the table have excluded her." (Fran, Passage 140)

While all family carers attempted to maintain normalcy during mealtimes, as the disease progressed and the difficulties with eating and drinking became more severe, this was

hard to achieve. At times, family carers were involved in decision-making regarding the abandonment of mealtimes either temporarily (e.g., in response to a choking episode) or on a more permanent basis when the physical limitations of the care-recipient meant that normal mealtimes were not possible. Participants experienced guilt when they could no longer provide support to care-recipients at the level required to enable their inclusion in mealtimes.

In instances where family carers felt that care-recipients had made changes to their eating and drinking routines and rituals or had withdrawn from certain aspects of mealtimes, either to reduce the burden on family carers or to enable family carers to continue to engage in their own food and drink-related routines and rituals, guilt arose. Some participants spoke of care-recipients refusing to participate in mealtimes or continue with oral intake due to the high demand required from the family carer to support these changes. The withdrawal of the care-recipient was often reported by participants as being introduced by the care-recipient as a one-off situation that gradually and subtly increased in frequency over time. Participants described experiencing guilt when they became aware that care-recipients were withdrawing from mealtimes and oral intake out of "convenience" for them:

> "She (care-recipient) knows I don't enjoy it (providing assistance with feeding). So I get a feeling that she's actually...-Sunday would have always been a day where I would give her her meal so she stopped having that. She doesn't feed on Sunday she doesn't have a solid meal on Sunday."… "Yeah, I think she's doing it for convenience for me. She is making that decision to, yeah."… "I think initially it was 'I don't want to have anything today.' And then that went on for a few weeks and became routine so it was just become…-and now I know she doesn't want anything to eat." (Fran, Passage 214)

It was not uncommon for family carers to avoid eating and drinking in front of care-recipients because of the guilt they felt given the care-recipient's level of disability, and the reality that this level of disability forced the exclusion of care-recipients from mealtimes:

> "It's hard for us to come in and have a full meal in front of her (care-recipient)."… "There are days when I'll probably not eat, very little, and then there are days when I'll have something but if I was to have something I would probably have it in work or at home, I wouldn't have it here. I would stay away. I would make it my business not to." (Hallie, Passage 32/42)
>
> "If I eat something different from him (care-recipient) it is generally something he wouldn't like. I wouldn't really be sitting down having a dinner that he would

> normally love to eat and he not be able to eat it. That wouldn't arise." (Deirdre, Passage 80)

Family carers often juxtaposed their ability to remain engaged in mealtimes with the care-recipient's inability to participate, and this further exacerbated their sense of guilt. In cases where there were regular family mealtimes within a wider family unit, family carer guilt was experienced when care-recipient withdrawal from the mealtime appeared to take place to assist in maintaining the integrity of the mealtime for members of the wider family unit.

Many situations were described by participants where they sought to avoid *immediate* feelings of guilt associated with feeding, swallowing and mealtime situations. However, participants also described occasions where they sought to avoid situations that could contribute to feelings of guilt *in the future*. Family carers were conscious that some of the decisions they were required to make in the context of feeding and swallowing difficulties could have long-term implications for themselves as well as other family members, and they attempted to minimise the risk of this as much as possible:

> "I just felt it was too much to put on them (children). It was hard enough as it was (feeding the care-recipient). And I suppose it was maybe, I didn't see it as my solo exclusive job that I didn't want anybody else doing it, that's not why it was…-I just didn't want in ten or fifteen years' time that they might think 'Dad forced us to do this and he forced us to do that.' Or 'I had to do this'. Or 'I had to do that.' I preferred it to be 'I did this for Mom (care-recipient), this is what I had to do and this is what we did as a family.' I think that might work better for them in the future." (Tony, Passage 62)

4.2.5 Maintaining hope

While sadness and loss, fear, anger and frustration, guilt and regret were common features of the emotional context for family carers, many carers also emphasised the importance of remaining hopeful as they lived with the illness and the resultant feeding, swallowing and mealtime challenges. Participants in this study described many instances where the ability to maintain hope enabled them to cope with the feeding, swallowing and mealtime difficulties MND brought in their lives and to support their family members with MND to navigate the associated consequences. For the most part, family carers refused to resign hope or "give up" in the face of this illness that would progress to profoundly impact the feeding, swallowing and mealtime function of their family member, as well as their own mealtime experience.

> "You are in a situation, you have to deal with it. So you are better to do it with a smile than crying."…"Crying doesn't help, I've tried it ((laughing)). So we just get on really, do the best we can. You have to look on the bright side, what can you do?" (Carol, Passage 106/194)

> "I wasn't giving in that there was something wrong. I never gave up hoping you know." (Steve, Passage 14)

> "We hope for the best. That's the way we live. We've been living like that for a long time now."… "I just take each day as it comes and hope for the best." (Gina, Passage 120/130)

> "It's fecking life. You just have to get on with it. You can't walk away." (Mike, Passage 52)

The maintenance of hope was reported to be more challenging for participants whose care-recipients were facing a rapid deterioration in their health, accompanied by fast-changing feeding and swallowing difficulties. Slow illness progression and a slower deterioration to feeding, swallowing and mealtime function was often associated with feelings of hopefulness and gratitude, although only when the care-recipient's QoL was at a level considered acceptable to the family carers:

> "Things are slow, nothing is taking place and it's great, long may it last." (John, Passage 86)

Family carers experienced internal pressure to remain both "positive" and "strong" to protect the ability of the care-recipient to cope with both the broader physical changes and the specific feeding and swallowing changes associated with MND:

> "I fell apart in the shower and Ian (care-recipient) saw it and Ian started crying too. But I thought 'I don't want to be upsetting him.' And that day I thought 'This is ridiculous, this is ridiculous, what am I doing sitting here?' And I thought 'There has to be learning in this, there has to be learning. I have to get off me pity pot. Because I can't sit here feeling sorry for myself.'" (Enid, Passage 146)

> "I try me best. It's just a matter of being as strong as possible for her (care-recipient) and giving her the best of the time that she has left." (Hallie, Passage 106)

> "I just said to…-my daughter and I were chatting one night and I just said to her 'The two of us will have to be strong for her (care-recipient).'" (Steve, Passage 52)

Participants reported being inspired by care-recipients to remain positive in coping with MND-related changes (including feeding, swallowing and mealtime function). Family carers expressed that the care-recipient's ability to remain positive demanded their own positivity:

> "She (care-recipient) is thinking positively. Of course we have some bad days, like everybody I think. But I think she is thinking positive and I am trying to think positive as well. As much as I can." (Rory, Passage 104)

> "Because my sister (care-recipient) is so positive, it made us all wipe our tears and get on with it. We were all trying to keep as positive for her. You don't want to be crying in front of her and making her feel down." (Iris, Passage 32)

Often care dyads were reported by the participants to have decided to remain positive as a strategy to enhance their outlook on the illness and the quality of their lives together:

> "We sit and we say 'We made the best of it.' And we have been very positive through it all and we say 'This is it, we are living life to the full. We are doing every possible bit. There is going to be no 'I wish I did.' We are going to do what we can.'"… "It's a wakeup call to say we have one life, this is not the dress rehearsal, it's the show. And we can live every day. We are getting fair warning to live a great life and that's the plan." (Enid, Passage 60/110)

> "We have stopped him (care-recipient) from saying 'My last outing, my last this (…), nothing for this now, death sentence.' So we have got rid of all that and say 'We could be gone before you.' We have to live our lives and live everyday as best we can." (Quinn, Passage 40).

Some of the participants in this study were philosophical regarding the presence of MND in their lives, expressing gratitude for the lives that they had had:

> "We have been very unlucky in coming down with this dreadful disease but at the same time we have had a good life." (Bonnie, Passage 164)

For the most part, the family carers believed that their ability to remain positive directly impacted the care-recipient's ability to live with MND and the associated disabilities, including feeding and swallowing disability. Many participants reported engaging in positive self-talk as well as using self-motivation strategies (including contextualisation and purposeful gratitude) to enhance their ability to remain positive in the context of the changes:

> "Just do the best you can. When you look around it could be worse." (Lisa, Passage 208)

When discussing changes to feeding and swallowing and the indication for aids and appliances supporting care-recipient independence, many of the participants reported instances where they had actively sought to take a positive outlook, presenting the care-recipient with silver linings to enhance acceptance:

> "He (care-recipient) was very annoyed about it (being unable to eat steak). And 'I love my steaks, and I can't eat them anymore.' And 'There's plenty of other food you can eat. You know a lot of other people are in that situation.' You know you have to talk it and get him to think 'Look, I'm not that bad. I can eat other things.'" (Quinn, Passage 60)

In addition to participants feeling encouraged to remain positive by care-recipients who were able to remain positive themselves in the face of this life-limiting illness, the ability of the family unit to accept the illness and manage illness-related complications such as feeding and swallowing disability as a team facilitated family carer positivity:

> "From that weekend on that was it, over really, the moping about. Once I seen them (the members of the wider family unit) in the house, jolly." (John, Passage 198)

Humour was used as a strategy to navigate illness-related changes and was discussed by the participants as a facilitator for family carers in their attempts to maintain positivity both for themselves and for the care-recipient:

> "Sometimes when he (care-recipient) is eating he drops a lot of it. I do say 'Put…'-give him the towel to put here (indicating onto the lap) because he just drops it all. It's all…-'Listen here, it's all dropping out of me mouth.' We all just make a joke of it you know because it's…-I'd say 'I'm after messing mine (mouth) you know, it's not that mouth.'" (Lisa, Passage 114)

For many participants, the ability to remain positive regarding all aspects of the illness including feeding, swallowing and mealtime challenges was expressed as essential for their own ability to cope with the situation they were in:

> "You have to be positive. We wouldn't be here if we weren't positive." (Peter, Passage 215)

The interaction between HSCPs and the care dyad was identified by many participants as a potential barrier or facilitator in the maintenance of hope. In some cases the interactions

of the care dyad with formal care providers contributed to the family carer's ability to accept the illness and cope with the feeding, swallowing and mealtime consequences. When HSCPs delivered care in a way which violated either member of the dyad's sense of hope, there was a negative impact on family carer engagement with feeding, swallowing and mealtime-related interventions:

> "When you get in front of a professional who then talks about 'Here's a powder that you are going to have to use' and gives you a box of it, there's just never any need to go there. At the time. But it's presenting a really bleak picture that isn't, that we hadn't reached at that point and she still hasn't reached." (Fran, Passage 204)

Conversely, when HSCPs delivered care in ways which facilitated family carer hope and positivity, the working relationships between themselves and family carers were enhanced:

> "I am satisfied that everything that can be done is being done and the people that we are dealing with (HSCPs) do nothing but instill a confidence in us. We don't come out saying 'Jesus, I've wasted bloody time.' We have never experienced that and that means a terrific lot." (Peter, Passage 160)

> "The SLT is absolutely fabulous and she certainly has Mark wrapped around her little finger. She is excellent, awfully nice and she handles everything very well."… "I think we have had a very good experience. Suggesting changes can be very difficult but if it's handled correctly. We would really speak very highly." (Deirdre, Passage 228/232)

> "You know there is <u>always</u> a positive coming out of it (clinic appointment). And Ian (care-recipient) keeps saying 'I'm so lucky I am walking in here.'" (Enid, Passage 102)

4.3 Unpredictability, uncertainty and a lack of control

4.3.1 Illness unpredictability

The ability to bear, brave and persevere with the consequences of MND-related feeding and swallowing disability was influenced by the unpredictable nature of MND:

> "Initially it was help with cutting something on the plate and then over a series of months you would go from that to using straws and then actually spoon-feeding (…) You're realising that that's going to be the <u>progression</u> of the disease, that's the way it's going to be. That has changed and there's still a lot more to come so

you don't even know what's around the corner. It's a gradual thing but scary at the same time because you don't know what's around the corner." (Fran, Passage 28)

Although the unpredictable nature of the illness for participants meant they were often in a state of flux, many reported being conscious of the implications for themselves as family carers to plan ahead in the event that a major complication compromising safety and QoL in the context of swallowing impairment could occur. Family carers typically sought to avoid discussions which highlighted potential deterioration in care-recipient status (e.g., suitability for adapted cutlery, candidacy for gastrostomy feeding) unless they were deemed essential to the provision of care. A high level of individual variation and unpredictability in the expression and progression of the illness was often cited by participants as a reason to frame care provision as reactive rather than proactive. In discussing the potential need for future assisted feeding, Deirdre explained:

> "The thing that I find the hardest, one of the hardest things to sort in my head is that everybody is different, that every case is different, therefore if you were in my position, me having a conversation with you (to prepare for changes) isn't considered beneficial. In so far as Mark (care-recipient) might be very different than the situation you're in." (Passage 214)

Family carers acknowledged that they risked being under-prepared to deal with feeding and swallowing complications arising from the illness given the expected pattern of change, and the time frame for these changes were not accurately predictable. Predictability and the ability to plan (when possible) enabled participants an opportunity to understand how potential changes could impact them, afforded the time they required to seek further information, and supported their own adjustment to changes ahead of the assumed responsibility to support care-recipients in accepting these changes. Despite the potential benefits of future planning, participants were universally reluctant to consider events beyond the present moment:

> "To a certain extent you are reacting and you are going with it and making the adjustments as they happen." (Fran, Passage 30)

> "If I was to think about all of the things which could happen, which might happen, I think I find it easier to deal with each day. And when something new becomes an issue, we deal with that. Because certainly if you were to pre-empt. I don't think it's at all helpful to pre-empt. We all know what may or may not happen. And I think (…) it's our way of -our mechanism is just to deal with it as it happens." (Deirdre, Passage 206)

Gastrostomy insertion as a potential management option in the context of MND was considered by family carers to be a particularly sensitive intervention, presenting a special case in planning. Discussions around candidacy for gastrostomy in this study were most often initiated by HSCPs. While participants understood the need for medical professionals to plan given time-linked candidacy criteria applicable for this medical intervention, inconsistencies were commonly identified between what HSCPs had predicted regarding the progression of swallow impairment for care-recipients and the actual progression of swallowing difficulties. As the predictions of HSCPs guided decision-making with respect to the urgency of gastrostomy, this could be problematic for family carers. Family carers were critical of interactions with HSCPs if they felt discussions regarding gastrostomy were premature:

> "A speech and language therapist at one point in terms of prepping her (care-recipient)…they decided early on to give her a button lift <u>well</u> in advance of her probably needing it so at that point the expectation was that she would end up having to eat modified food, liquidised food…but that never developed as it was expected and she never got to a stage where she couldn't swallow and so she still can swallow."… "The advice was all coming <u>before</u> it was necessary. I suppose if anything I and Connie were led to believe that everything would be a lot more difficult. That everything would be liquidised. That Connie would need liquidised (…) so that was what we expected that she was just not going to be able to handle anything at all. And it just didn't turn out that way." (Fran, Passage 2/182)

There was also a danger that discussions around the suitability and appropriateness of gastrostomy feeding could occur too late:

> "I felt annoyed that he (GP) had not picked that up. My Mum (care-recipient) was admitted to hospital and we were told that she wasn't a candidate for PEG (percutaneous endoscopic gastrostomy). I can't remember was my Mum on a modified diet at the time but I did feel annoyed that it wasn't picked up before." (Anthea, Passage 272)

> "They said it could be ten years before she (care-recipient) could really lose it altogether. They were on about the swallow and all these things. I said to the nurse, I say 'This woman is not going to last ten years.'" (Steve, Passage 24)

The unpredictable nature and progression of the illness required flexibility in family carers' approaches to management, and without adequate resources to support family carers to be able to achieve this flexibility, they could become overwhelmed in their role.

4.3.2 Reduced sense of control

Lack of control was universally expressed by participants in this study in relation to the presence of MND within the family unit and the complications arising from MND including those impacting feeding, swallowing and mealtime functioning. Many participants reported resigning control in a broad sense as part of their acceptance of illness-related changes including those impacting feeding, swallowing and mealtimes:

> "You can't do anything else. There's not another thing you can do about it. So. What's coming for you is coming for you." (Lisa, Passage 208-extended)

> "Things change and you just have to deal with it, you know." (Gina, Passage 138)

> "It was going to happen. There was nothing we could do about it." (Tony, Passage 84)

Illness-related complications of sudden onset and rapid progression heightened the lack of control the participants in this study experienced:

> "It just happened so suddenly and he (care-recipient) was so difficult to understand all of a sudden and he couldn't really eat anything without choking." (Karen, Passage 2-extended)

Although a heightened sense of overwhelm was identified by participants who were providing care in the context of a rapid illness progression, participants providing care to care-recipients with a slow illness progression were not free from challenges associated with the changeable nature of the illness:

> "I'm always aware that this could go downhill very, very quickly."… "I was very concerned about how quick it would change." (Iris, Passage 134/150-extended)

Despite lacking control regarding the presence of the illness and the illness trajectory, participants identified a tendency to exercise control where they could, and when doing so meant they could improve the health, safety and QoL of care-recipients. How control was enacted varied amongst family carers and was reported by the participants to be influenced by many conditions. The nature of the relationship and pre-existing power dynamic within the carer dyad, the individual's need to optimise their own sense of control, and participants' delineation of their role as a family member with their role as a caregiver, were all identified as conditions which could influence family carer enactment of control in feeding, swallowing and mealtime situations. Within the care dyad, each individual's

understanding of the other's involvement in decisions on care (e.g., the level of input they wished to receive from HSCPs) also impacted the exercise of control.

4.3.3 Uncertainty, with the exception of death

All carers acknowledged uncertainty as a feature which influenced their psycho-emotional context and ultimately actions and interactions which took place within the care dyad, as feeding, swallowing and mealtime changes were navigated by family carers within this context of uncertainty. Within the broader illness-experience, participants described the nature of the diagnostic process, a prolonged diagnostic process, and errors in diagnosis as contributing to the sense of uncertainty in the initial stages of the illness and influencing the experience of specific disabilities (including swallowing disability) for participants from very early on:

> "Every consultant we went to I said 'You still haven't proven to me, you still haven't proven to me, it could be anything. It could be big toe syndrome, I don't know, you can't prove it to me.' Eventually the consultant sat me down and said 'Nonnie, you're right. I can't. That is why we have done all the brain MRIs (magnetic resonance imaging) and all the body MRIs and it is literally a process of elimination.'" (Nonnie, Passage 188)

> "There (in the care-recipient's country of origin) they say she (care-recipient) had Motor Neurone Disease. When she came back here we already knew what happened. But the doctors said it doesn't matter what they say in our home country they don't have the proof for that and the diagnosis was really hard. So when they decide the diagnosis it was taking four times to go to the neurologist." (Rory, Passage 116)

Specific instances of uncertainty around aspects of the participants role in supporting care-recipient feeding, swallowing and mealtime difficulty were described in this study. The procedures undertaken by family carers during meal preparation, practical aspects of diet and fluid modification, administration of oral and enteral feeds, the use of nutritional supplements, and the contribution of the participants to decision-making regarding specific interventions were all examples of how uncertainty could arise for family carers:

> "I've never dealt with this illness, so I don't know as far as it goes when she (care-recipient) needs breathing intervention will she need a tube (for feeding)." (Iris, Passage 74)

> "I was doing it myself and getting the food and my daughter was making the food and between us we were doing it together and we didn't know (what we were doing)." (Steve, Passage 20)

The most consistent facilitator for family carers supporting care-recipients with feeding, swallowing and mealtime disability within the context of uncertainty described by the participants of this study was the strong self-belief that family carers were "doing their best", and an acceptance that this was all they could do:

> "As long as you know yourself you are doing the best you can…I'd be of the opinion that we are doing the best we can. And that if he (care-recipient) did upset himself (whilst being fed) it wouldn't be me in particular that it's just him having a frustrating day." (Mike, Passage 156)

The participants in this study identified that their psychological status, personality type, and temperament, as well as their ability to accept the presence of illness within the family unit and cope with the loss of control associated with illness presentation and progression, were central to their ability to navigate feeding, swallowing and mealtime challenges in the context of uncertainty. Previous experience caring for individuals with disability or life-limiting conditions and having access to a family unit that was supportive and inclusive of individuals with disabilities was reported to improve the participant's ability to cope with uncertainty. The personality and temperament of care-recipients, their own acceptance of and ability to cope with the series of losses associated with MND (including the loss of mealtime normalcy), and the quality of communication within the relationship between the family carer and the care-recipient predating the diagnosis were also important facilitators of care identified in this study.

In the face of MND as an unpredictable illness, participants expressed an acute awareness that the only real certainty they had was the fact that their family member with MND would eventually die from the illness:

> "Whether he (care-recipient) dies in six months or whether he does in a year or two years ((throat clearing)) you know it's coming." (Mike, Passage 232)

> "It is inevitable what is going to happen." (Tony, Passage 46)

> "You don't (…) know that it (the illness) is going to go on for so long. You know that there is going to be a period (of deterioration in swallow) and that period is going to be part of it (the illness). But it will end." (Fran, Passage 124)

> "The future I need to think about but at the same time I don't want to think about the future because that's when he's (care-recipient) not here." (Karen, Passage 52)

For the most part participants were uncomfortable with the uncertainty of the illness and its progression, but were torn between the unease associated with this uncertainty and the confrontational nature of visualising a future which involved the certain death of their family member. Family carer involvement in planning in advance of swallowing changes was acknowledged to be essential at times by the participants but presented a challenge.

4.4 Remaining present in the moment to maintain hope

4.4.1 Living in the moment

All participants in this study, regardless of the severity of the immediate, observable consequences of the illness (including feeding and swallowing difficulties), expressed a desire to avoid living beyond the present moment:

> "We are just trying to deal with each thing as it happens." (Deirdre, Passage 60)

> "We just deal with it as it is." (Enid, Passage 64)

> "If people know what lies ahead it can be off putting for getting on with today." (Carol, Passage 74)

Family carers were often unable to visualise how potential changes in care-recipient feeding and swallowing status would impact them in the future; doing so appeared to threaten participant's mental health and negatively impact their ability to bear the illness:

> "I couldn't see it (gastrostomy feeding). I can't picture it. I actually can't picture it. Because I mean this table is for eating, it's all about James (care-recipient). He wants people to be sitting around it and eating. I can't pic…-I have no idea. I just don't have an answer. I have no picture in my head for that." (Nonnie, Passage 154)

Forced acknowledgement of the unavoidable changes associated with MND violated the sense of hope which was necessary for participants in coping with MND:

> "I didn't seek out information as to what was going to happen down the line because I didn't want to know. I remember at the start, I remember watching a documentary on Motor Neurone Disease and it was really graphic it was like a

> horror film and I turned it off, I said 'I'm not going to look at anything else.'" (Anthea, Passage 335)

The emphasis on living in the present moment was reinforced by the participants' consensus that MND is an unpredictable illness. The unpredictability underpinned some of the participants avoidance of information gathering in respect of how the illness and the feeding and swallowing disability would evolve and in pre-empting the consequences of future changes to feeding and swallowing status:

> "It's all these things. And they might never happen." (Bonnie, Passage 132)

> "You're working with somebody to deal with things happening. As opposed to looking two three years ahead to something that might not happen." (Fran, Passage 208)

In the context of feeding and swallowing impairment, decision-making around the potential for gastrostomy tube insertion forced future planning, not only for the care-recipient but for family carers who were either actively or indirectly involved in the process. This was identified as a potential threat to the hope and optimism of the carer in coping with the illness.

Typically, family carers considered it "no benefit", "unnecessary", and "not at all helpful" to pre-empt what the future might bring. Predicting the future in the context of MND for many represented a life taken over by the consequences of the illness. Under some circumstances, family carers felt it was essential that they be involved in early planning regarding their management of a potential deterioration in care-recipient feeding and swallowing ability into the future. Quinn and Oliver reported that being forewarned regarding likely swallow deterioration allowed them time to "think ahead" and "gain control of the situation". These participants felt that advance notice enabled them to process their own emotional reaction to potential changes and understand what it would mean for them prior to being in a position where they felt responsible for assisting the care-recipient to emotionally navigate these likely changes:

> "I'll have the thinking done (regarding gastrostomy) and then when it comes to him (care-recipient) (…) then it will be easier for him rather than the two of us being upset together." (Quinn, Passage 108)

The care-recipient's psychological status and their ability to accept the diagnosis and cope with the feeding and swallowing consequences of the illness, were reported by participants as crucial to their use of forward planning as a strategy to assist care-

recipients in managing change. Care-recipients who were considered by family carers as "prone to depression", those who were "worriers", and those who were "in denial" were considered by family carers to be more at risk of negative mental health consequences when facing the potential likelihood of further deterioration in feeding and swallowing function. Under these conditions, participants looked ahead to plan for changes, despite the negative consequences which could result.

4.4.2 Learning in the moment

The shared preference of the participants in this study to avoid living beyond the present moment was overtly referenced by participants as having an impact on their sense of preparedness for potential changes in the future, particularly when new skills were expected to be acquired, as in the case of management of feeding and swallowing impairment:

> "There may be times, maybe there will be professional help wanted down the line. But for now we are coping and if in the future we need to learn new things, we will learn new things." (John, Passage 156)

> "We just played it by ear really as we've gone along. Take things as they come and then when you come across a difficulty you address it then." (Carol, Passage 136)

Some participants reported that they had identified useful resources they might use if new skills were required to support care-recipients with aspects of feeding and swallowing. If a change to the care-recipient status requiring a new skill occurred, the carers often had a plan to follow. Typically, they had identified experts both within and beyond the family unit whom they could use as a resource:

> "When we start to see her (care-recipient) with her (deteriorating) chewing and swallowing we will get straight onto it and get the training. Or we will have to get the nurses back out for another kind of meeting to go through it to give us advice because they know. We don't know anything about it, we are learning." (Iris, Passage 40)

Participants referenced shopping, cooking, diet and fluid modification, fortification of oral intake, surveillance of nutritional status, management of choking events, feeding individuals with self-feeding difficulties, and managing gastrostomy tube feeding as specific skills they had acquired as family carers, given little or no notice:

> "I don't think I ever fed anybody before so it was new to me" (Mike, Passage 152)

Many participants referenced experiencing a lack of confidence in the beginning when completing new care tasks required of them to support feeding and swallowing difficulties. However, they explained that they had quickly become “experts” themselves and that feeding and swallowing orientated care tasks often became “natural” soon after the remit of their care responsibilities had been extended.

4.5 Conclusion

This chapter has demonstrated that the experience of feeding and swallowing impairment for family carers of PwMND is situated within the context of the broader experience of MND. The complex emotional context underpinning the experience of the participants in this study is characterised as one including sadness and loss, fear, anger and frustration, guilt and regret, often reported by family carers as apparent prior to formal diagnosis of the illness, and in some cases remaining present long after the death of the PwMND. Participants in this study unanimously reported that feeding and swallow impairments were heavily embedded within and inseparable from the broader context of MND-related impairment. Specific attention to the experience of family carers who assist care-recipients with feeding and swallowing impairment has explicated a unique insight into how the experience of feeding and swallowing impairments intertwine with the wider illness experience for family carers and influence how family carers approach and interpret mealtimes. Participants in this study indicated that they had no control or choice regarding the presence of MND or MND-induced feeding, swallowing and mealtime complications in their lives, or the ultimate impact this had on the roles and relationships within the family unit. Nonetheless, family carers endeavoured to remain hopeful as they assisted care-recipients to navigate feeding, swallowing and mealtime complications. The participants in this study provided evidence that family carers bear, brave and persevere with feeding, swallowing and mealtime consequences of MND and, in many ways, share the impact of the illness with care-recipients as they “live the illness” with the person they support in feeding, swallowing and mealtime function. The ability of family carers to manage feeding, swallowing and mealtime challenges of MND as they present each day and their ability to access support from other informal and formal carers enhanced their experience of feeding, swallowing and mealtime changes induced by the illness.

This chapter presented the psycho-emotional landscape of family cares within which the experience of mealtimes, and actions and interactions with care-recipients and with the wider family unit during mealtimes were situated. The next chapter will present the core category *protecting* and explain the significance of *protecting,* in framing family carer behaviour during mealtime events.

Chapter Five

Core category- *Protecting:* The essential element framing the feeding, swallowing and mealtime experiences of family carers

"I'm always watching her. Not in a way that would affect me or that I'd over think things but I'm definitely cautious of her. And it's the safety of the children as well that really needs to be considered. So I would watch her and I'd have no problem saying to her, in a nice manner. But I would be practical about it and let her see where I'm coming from and what…-'If we don't address the matter what would happen to you and the kids?' You have to…-as much as she wants to be independent and keep going how she is going, she does not have to be selfish in the sense that if stuff isn't happening for her, she does need to let us know. Because it's the kids that would suffer. You know if she does choke and they can't help her and she dies in front of them, how would that be?" (Iris, Passage 78)

5.1 Introduction

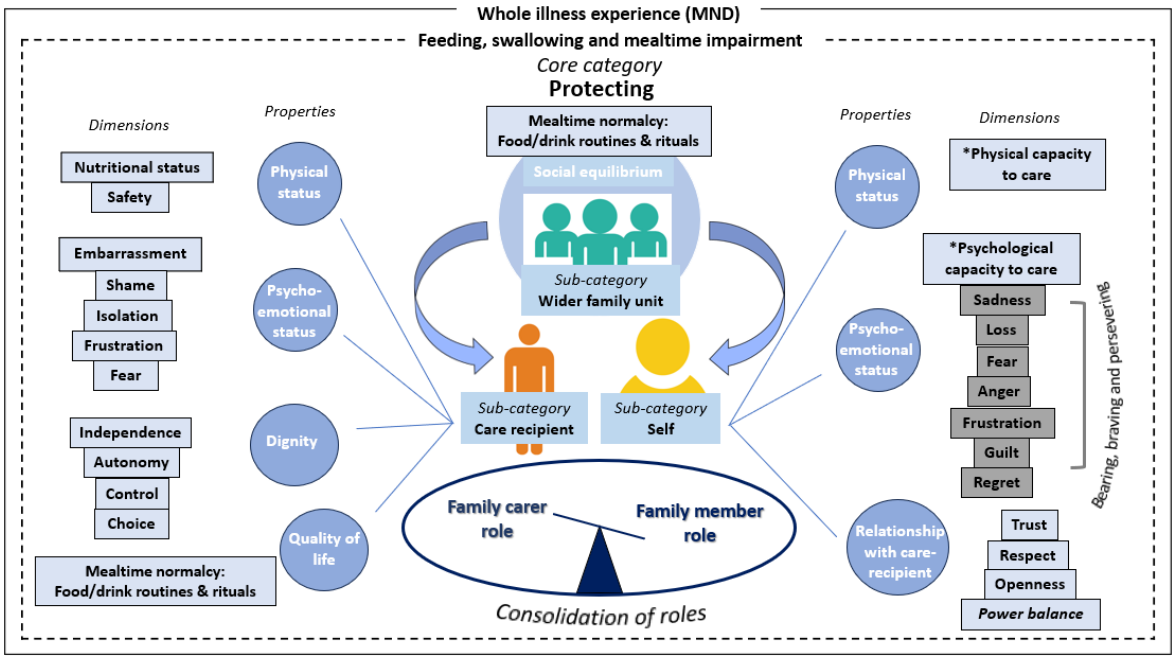
In this study, the essential element framing the feeding, swallowing and mealtime experience of family carers who provide care to support family members with self-feeding and swallowing difficulties was identified as *protecting*, and as such, *protecting* has been designated the core category. Participants were primarily concerned with protecting either the care-recipient, the wider family unit or themselves when care-recipient feeding and swallowing difficulty arose. Examples of family carer protection extended not only to the physical and psycho-emotional domains of health but also to the psycho-social domain of health for care-recipients, participants, and other members of the wider family unit routinely present during mealtimes. Family carers in this study sought to reduce the impact of the feeding and swallowing consequences of MND which were experienced first-hand by the care-recipient and shared by members of the family unit (as well as themselves) as third parties. Participants mitigated the impact of feeding and swallowing impairment within the family unit by conceptualising and enacting their role as a family carer, consolidated with their traditional role within the family unit, and this was underpinned by the urge to *protect*. For the participants of this study, *protecting* presented as a universal but fluid, multi-layered and multifaceted concept, significant in framing subsequent family carer action and interaction within the context of feeding, swallowing and mealtime situations. *Protecting* was orientated not only towards care-recipients but towards members of the wider family unit involved in feeding, swallowing and mealtime situations, including the family carers themselves. Family carer engagement with formal

healthcare providers and (at times) members of the wider community was influenced by the orientation and intensity of the family carer's desire to *protect*.

This chapter provides the personal accounts of participants in this study which illuminate *protecting* as concept universal to the experience of family carers who support care-recipients with feeding and swallowing disability secondary to MND. This chapter presents the core category *protecting* as central to the experience of feeding and swallowing impairment in the context of MND for the participants in this study by initially demonstrating the application of *protecting* by family carers to the 1) physical status, 2) psycho-emotional status, 3) dignity, and 4) quality of life (QoL) of the care-recipient. Following this, the family carers' application of *protecting* to the social equilibrium of the wider family unit is described. The properties of the category *protection of self*, including protection of family carer's 1) physical and 2) psycho-emotional status, and family carer's protection of 3) the existing relationship with the care-recipient, are systematically presented in order to provide a comprehensive account of how family carers prioritised and focused protection, and on what basis their need to protect was initiated, maintained, or altered. Figure 4 below depicts the core category *protecting* and its centrality to the experience of family carers.

Figure 4.

The core category *protecting* applied to the family carer experience of feeding, swallowing and mealtime challenges in MND



The mealtime experience of the family carers in this study, framed by *protecting*, was shaped by numerous care-recipient-centred conditions, such as the severity of the illness and extent of care-recipient feeding and swallowing disability, as well as by the family carers own unique set of causal and contextual conditions. These conditions were interwoven with the characteristics of the family unit in which care was situated and have been highlighted in this chapter. Distinct features underpinning the operationalisation of *protecting,* that is, the action and interactions which arose for family carers given their engagement in *protecting*, are introduced in this chapter with barriers and facilitators to the enactment of *protecting* as identified by participants raised for further discussion in chapter six.

Consistent with the previous chapter (chapter four), the data extracts presented in this chapter include transcription conventions, and the reader is directed to Appendix H for the full list of conventions used.

5.2 Protecting the health status of the care-recipient

Participants in this study were concerned about the physical as well as the psycho-emotional consequences of feeding, swallowing and mealtime disability for care-recipients and this influenced their experience of mealtimes. Some participants reported observing changes in the physical status of their family members, including changes to self-feeding and swallowing ability, as the initial symptoms of MND. In these cases, a sense of protection arose early in the disease process. Prior to diagnosis, *protecting* by family carers coincided with the detection of physical symptoms associated with swallowing impairment, consistent with the presence of an underlying illness:

> "It was only towards the last couple of months before she (care-recipient) got diagnosed that I was looking up stuff and googling and it came up Motor Neurone Disease and you're praying that it's not."… "It was a matter of sitting her down and asking her questions of 'What is going on? Do you feel any different?' and she said 'I don't know.' It was like she had no control over her swallow."… "After that it came to a head and we said to my Mam 'Mam we have to get this sorted whether we go private, because we have to get you seen.'" (Hallie, Passage 12-18)

Participants reported encouraging care-recipients to access medical attention due to the feeding and swallowing changes they had observed. Some participants also suggested care-recipients access second opinions when there was a perceived risk of misdiagnosis in accounting for swallowing difficulty. For all participants, the intensity of the need to "protect" the care-recipient increased as the illness progressed.

5.2.1 Protecting the physical status of the care-recipient

The focus of family carer protection from early in the disease pathway related to the optimisation of physical outcomes and prevention of physical harm to care-recipients, including negative consequences of swallowing impairment. Participants described the sense of responsibility they felt to protect the physical status of care-recipients during eating and drinking as "ever-present". This translated into a constant urge to remain watchful over care-recipients:

> "We won't leave him (care-recipient) in the house on his own if he is going to be eating."…"If I go out I make sure he's eaten even if it's for five or ten minutes." (Quinn, Passage 24/42)

The desire to protect care-recipients from physical harm when eating and drinking impacted the living arrangements of the participants who had been living separately from the care-recipient prior to the diagnosis. Anthea, Hallie, and Una reported making arrangements to reside (in part) with the PwMND as soon as the diagnosis had been confirmed:

> "I would stay over here (with care-recipient) a lot now…especially the last while (as swallowing impairment has increased)." (Hallie, Passage 68)

The intensity of the family carer's urge to protect care-recipients physical status increased when family carers perceived that care-recipients were having difficulty accepting the diagnosis and/or the physical deterioration (including the deterioration to swallowing function) that could eventually lead to death:

> "I just said 'Look Dad (care-recipient), you don't understand what this is. It's bad, it's <u>not good</u>, they don't have a treatment for it.' Dad just said 'No, I'm strong, I can't, I'm great.' He's off to Lourdes and he thinks he's going to have a miracle, he thinks that Jesus is going to appear and put his hand on his shoulder and say 'You're cleared.'" (Karen, Passage 104)

5.2.1.1 Protecting care-recipient nutritional status

Participants sought to prevent complications which could arise for care-recipients when eating and drinking, consistently emphasising a desire to optimise the nutritional status of the care-recipient:

> "I just mentally keep a note of what he (care-recipient) takes during the day and I'd say 'Ian, you've had nothing for lunch'"…"I'm conscious that we have to work on this to build it up together." (Enid, Passage 52/92)

> "There are two things we were saying we have to be careful about. Colds because of the chest and losing weight. So conscious that she (care-recipient) is able to get enough nutrients in."… "If her plate is clear it's great but if not, say if there's a third of the dinner left you have to think of that over the period of a week. And that adds up to missing several dinners you know when you add up those thirds." (Carol, Passage 10/88)

Many participants closely monitored the care-recipient's oral intake. When care-recipient swallow function was deteriorating and gastrostomy feeding not yet established, participants felt responsible for maximising the nutritional status of the care-recipient to avoid unnecessary medical appointments, admissions, or interventions for the purpose of nutritional optimisation. Participants caring for care-recipients who were dependent for meal preparation and feeding often reported being consumed with the responsibility to maintain the nutritional status of the care-recipient.

Being able to maintain the nutrition, hydration, and medication status of individuals dependent for oral intake when early satiety or care-recipient refusal of intake was co-occurring was challenging for family carers:

> "Trying to feed him (care-recipient) something that he didn't like (modified consistency food) you know. It's just the volume, he couldn't get any volume into him because he had no interest at all and it was just such an effort." (Mike, Passage 10)

> "It's very hard to feed someone who is not hungry. And Mark (care-recipient) isn't. He can feel full most of the time so it's to really encourage him to eat something." (Deirdre, Passage 4)

> "It was a challenge getting my Mum (care-recipient) to eat and encouraging her to eat."…"I would have wanted her to eat during the day when she was at her best but I would've pleaded…-I would have tried to encourage her during the day to eat." (Anthea, Passage 74/248)

Participants described strategies they used to support and enhance care-recipient intake, such as ensuring a "back-up" meal was available to avoid care-recipient abandonment of the meal in the event of difficulty. It was not unusual for participants to report preparing

multiple menu options for care-recipients when care-recipient swallowing ability was variable:

> "I did something last night and he (care-recipient) just couldn't swallow it and just couldn't chew it and that was bad luck it just has to go off the thing (menu list). Em (…) I think he'd had it maybe a month ago and he was alright and I had an alternative. I had an alternative available." (Deirdre, Passage 28)

5.2.1.2 Protecting the care-recipient from choking

Choking was one of the most prominent negative physical sequelae that participants in this study referenced when describing their endeavour to protect the care-recipient from physical harm. Choking was discussed as a central focus for family carers who were seeking to maximise the physical safety of care-recipients when they were eating and drinking:

> "She (care-recipient) came looking for me and she…-I was 'Can you breathe?' And she was 'No' going like this (universal gesture for choking). I gave her the back blows on the back and I was giving her the thrusts as well and she got whatever it was up." (Hallie, Passage 8)

> "There's been instances where things have gone with his (care-recipient's) breath and I might have to clap his back." (Deirdre, Passage 106)

The experience and training of the participants in the management of choking ranged. When family carers received formal training in First Aid, this training often took place prior to their family member's diagnosis. Advice on the management of choking specifically for PwMND was usually sought by family carers from medical professionals:

> "I think maybe two clinics ago I did ask one of the doctors should I be refreshing the Heimlich manoeuvre? Is this something that I'm going to have to deal with?" (Carol, Passage 44)

Some participants in this study reported encouraging care-recipient application of compensatory strategies aimed at improving the safety and efficiency of oral intake. Family carers described prompting care-recipients to take small volumes of food and drink with slow rate, alternate fluid sips with food mouthfuls, and avoid talking while eating and drinking to reduce potential risks to the physical status of the care-recipients:

> "I would always be keeping an eye on her (care-recipient) to make sure that she's a drink with her. And I would be telling her to keep a drink with her at all times if

she would be eating”… “Just in case it went down the wrong way.” (John, Passage 43/47)

Participants also encouraged care-recipients to expectorate any food or fluid items they felt could cause an adverse effect. They urged care-recipients to adhere to diet and fluid consistency modifications and avoid “unsafe” food and fluids, paying particular attention to this when planning, preparing and providing food and drinks:

> “She (care-recipient) would have wanted one of those (hard sweets). And I would have said to her ‘Look that could be dodgy, that could go down the back of your throat.’ You know.” (Tony, Passage 100).

> “A few months ago (we) changed the diet because she (care-recipient) wants this (swallow) to improve. So now maybe cooking the lunch, the dinner, all this making mashed potato.”… “Eating in this moment is not a problem because we have changed the diet for her.” (Rory, Passage 62/80)

Completing on-the-plate modification of food was often required of family carers who cut up foods for care-recipients prior to presentation to optimise not only the safety but also the efficiency of oral intake.

5.2.1.3 Protecting safety in advanced illness

Family carers prioritised care-recipient safety prior to the diagnosis when swallowing impairment and choking were early signs of illness. The emphasis on care-recipient safety continued for many participants throughout the initial stages of the illness. Protection of the care-recipient from an acute, catastrophic choking event was a primary goal universally shared by family carers. However, the care-recipient’s experience of comfort during oral intake was also a concern for the participants in this study. Many participants reported preparing food and drinks for the care-recipient’s comfort (only) during the advanced stages of the illness, investing time and effort into this process despite very limited care-recipient intake, high care demands, and often limited resources:

> “She (care-recipient) can’t even drink now, even a cup of tea she will take maybe one or two sips out of it and it will still be left there.” (Hallie, Passage 92)

> “In the morning I’d have to get her (care-recipient)…-I was going through the motions of getting her breakfast but she wasn’t even having it. She was putting it into her mouth. I would cut up the crust off the bread and then I would cut the bread up into tiny little cubes and I could see that she was only, she was having problems chewing, chewing her food and everything had…-eventually everything

had to be soft and mixed."… "And I could see that she wasn't able to swallow but she insisted on me doing it. Up to the very end." (Oliver, Passage 50/56)

Challenges could arise for family carers when care-recipients requested they be provided or assisted with food and drink items that family carers considered were unsafe. This was particularly difficult when care-recipients were physically unable to self-feed. Family carers described these situations as "moral dilemmas", and despite their own discomfort, were often led by the care-recipient's preferences in these situations. As Anthea stated:

"We knew that my Mum (care-recipient) was a cautious person herself and she had this…-we trusted her to gauge whether or not she was fit for something (to eat)." (Anthea, Passage 72)

Although not often, some family carers reported that they had been unable to provide problematic food and drink items following observation of care-recipient difficulty during intake and requested that care-recipients avoid troublesome items:

"Water is ↑particularly difficult. I do not know <u>why.</u> I <u>have</u> asked him (care-recipient) to not drink the water very cold. I do think that it hits the vocal cords and tends to tighten things." (Nonnie, Passage 10)

Some participants verbalised the discomfort they felt in situations when they felt forced to feed the care-recipient food or drinks they felt could be unsafe:

"They are putting the taking of this risk on the other person, which is not fair because it puts the carer in a very difficult position." (Carol, Passage 206)

When health and social care professionals (HSCPs) recommended diet and fluid consistency avoidances for the person with MND (PwMND), this could present an additional layer of complexity in the management of feeding and swallowing disability that family carers were required to navigate:

"We all did things that weren't advisable. Like you'd be so nervous giving it (unsafe food item) to her (care-recipient). You <u>really</u> didn't want to be giving her this food. I kind of knew. I knew that if it's on this sheet and you know yourself not to give her biscuits. I knew not to give her biscuits. Yeah and I do remember speaking to my Aunt about it and being 'What are we to do here? We're doing something that's wrong.' And in a way if you are doing that you are facilitating. There was a massive conflict there, not between us but an internal conflict with each of us in that we were giving my Mum food when we knew it wasn't the best practice but she was, she was asking for this." (Anthea, Passage 236)

Managing similar situations to those described by Anthea (Passage 236) was additionally challenging for family carers when the care dyad felt HSCP goals were misaligned with their own. More commonly, family carers reported being united with HSCPs in shared concerns around eating and drinking:

> "There were lots of occasions actually this year when she (care-recipient) was in the hospice and it was difficult for her to drink the water, she couldn't use the straw to suck the water up so what she was doing was eating ice cubes. She was taking ice cubes in her mouth and that was also…-not just me but the staff inside and friends visiting at the time, she was adamant 'No, I want ice cubes. I want it. I want it.' So we had to give it to her. We told her it was dangerous 'This could go down the back of your throat.' She didn't care." (Tony, Passage 100-extended)

Care-recipient safety was prioritised for the most part throughout the early stages of the illness and tended not to be foregrounded by participants as strongly towards the later stages of the illness. In the late stages, care-recipient QoL was paramount. The risk to physical safety associated with "unsafe" diet or fluid intake was interpreted in the context of a certain loss of life (in the near future) as part of the uncontrollable illness process. Mike described conceptualising these scenarios as the "last chance" the care-recipient might have to eat or drink something they love. Family carers often supported care-recipient intake under these circumstances despite the inherent risk; to do so seemed to afford care-recipients the opportunity to "say goodbye" to a loved food or drink item:

> "If he really did want it (food considered unsafe) why would you (advise against it)? It's not like he's going to have many opportunities after that to enjoy his oysters." (Mike, Passage 164)

5.2.2 Protecting the psycho-emotional status of the care-recipient

Protecting the care-recipient for family carers applied not only to the physical health dimension of the feeding and swallowing difficulties care-recipients were experiencing but also to the psycho-emotional consequences of the impairment for the participants in this study. Protection of the psycho-emotional status of the care-recipient was frequently discussed by participants in relation to protecting the care-recipient from embarrassment, shame, isolation and frustration due to the feeding and swallowing difficulties caused by MND which inevitably altered mealtimes:

> "It was a struggle bringing him (care-recipient) in here and trying to feed him and he would get frustrated and of course that brought a lot of emotion out as well for

him. He'd get weepy and upset and I mean a lot of it was to do with him accepting his own condition."…"Just trying to comfort him as best you can. I don't really say a whole pile."…"I think when he was still feeding himself he was conscious of people watching him then, struggling with the fork. You try to naturalise it. To a certain extent. I didn't try to make a big deal about it." (Mike, Passage 64/134)

5.2.2.1 Protecting the care-recipient from embarrassment and shame

Almost all participants in this study gave accounts of witnessing care-recipient embarrassment in relation to their feeding and swallowing disability. The exception to this was in instances where participants were providing care for care-recipients whose illness was in the early stages, with mild (almost undetectable) feeding and swallowing impairment, and where care-recipients were managing easily with minimal need for compensatory strategies or assistance from family carers. Many participants described challenges experienced by care-recipients when sharing meals in social situations. Most participants reported that care-recipients disengaged from social situations when feeding and swallowing difficulty arose. At times, family carers made attempts to encourage the care-recipient to remain engaged in social meals, particularly when social eating was a well-established mechanism for connection within the care-recipient's relationships:

> "We used to enjoy going out and we talked about going out. And he (care-recipient) was just saying he was uncomfortable going out. It got to the point where he would say 'Look, I don't feel comfortable about it because I can't eat and drink.' I'm saying 'Well look (…) we <u>should</u> still go out and either- well some people still do, for whatever reason four people could be out and one person could just say 'Look I'm just not hungry, I'm not eating.'" (Bonnie, Passage 34)

Although family carers described encouraging care-recipients to remain engaged in mealtimes in order to maintain social equilibrium, social connections, and a sense of normalcy, when there was a risk that embarrassment could occur in the context of social eating, participants tended to support care-recipient disengagement:

> "There was one incident where it happened where he (care-recipient) coughed in a restaurant where it was really what he had ordered."…"He had to get up and I started patting his back and of course that meant staff came over and actually very kind."…"I was aware of what the problem was whereas people in the restaurant may not have. But I felt sorry for him definitely yeah."… "He would have said something like 'You're minding a crock' you know. He'd have been…-we would

have talked about it."…"He'd have been embarrassed ((becoming teary momentarily))." (Deirdre, Passage 154-164)

"When we were going out there was this one time, I'm not sure what he (care-recipient) had but he had to take something out (of his mouth) with a tissue and I mean that was the worst thing."… "He had to take it out. And that's a difficult thing, but again that can happen when you are perfectly normal, you're having a steak or something."… "I think just being embarrassed a bit about it and he wouldn't be one to make a fuss normally whereas I would be more. But for him, it would be the sort of thing that would make him more inclined to put him off going out again or eating again, out." (Bonnie, Passage 108-116)

Family carer support for the withdrawal of the care-recipient from social eating situations was reported more frequently by participants who were caring for family members with a higher degree of disability or functional limitation. This included situations where care-recipients required supports to eat and drink comfortably, and with those care-recipients who were considered to be at higher risk of an acute complication of swallowing impairment arising during mealtimes.

Care-recipients who were reliant on aids and appliances designed to optimise safe and efficient eating and drinking (e.g., adapted cutlery) were generally not encouraged by the participants in this study to use them when out in public. Both members of the care dyad tended to seek to reduce the visibility of the feeding, swallowing and mealtime disability:

"He (care-recipient) said he didn't mind (going out and) not eating but he didn't want to have say with the straw, or me (feeding)…-which I can understand because we have the mugs with the mouth things (spout) which are very good but he would rather not use those going out." (Bonnie, Passage 36)

"In the beginning when she (occupational therapist) suggested it (adapted cutlery) he wasn't ready for it but once it became apparent…-Now having said that I don't bring them when I'm going to a restaurant or I don't bring them when we are going to somebody else's house or anything like that." (Deirdre, Passage 66)

Upper limb weakness, causing difficulty for care-recipients to self-feed, as well as a reduced lip seal, was reported by participants at times to result in "messy" care-recipient eating. Some participants described the optics of care-recipient eating as "awkward" or even "unattractive". Messy eating was considered by family carers to represent a potential threat to the psycho-emotional status of the care-recipient, consistent with shame and embarrassment. Family carers described strategies they used to reduce or compensate

for care-recipient's messy eating, offering protection from any unnecessary embarrassment or shame:

> "I would ignore it (messiness of eating) and just dab it off with the tissues you know. I wouldn't bring it to her (care-recipient) attention. I mean we had a steady flow of tissues here. Rolls and rolls of it. And I used to put a tea towel under her chin. We were going through ten tea towels a day." (Oliver, Passage 58)

> "Yeah because he (care-recipient) was after changing his trousers (to black), he had great trousers and -beige trousers and it's easier just to do that (reducing visible soiling) you know." (Lisa, Passage 116)

> "Liquid can be a problem you know with the dribbling. She (care-recipient) would be self-conscious if we were in a restaurant, so we just don't (go to restaurants)." (Carol, Passage 28)

Feeding dependence and the requirement for family carers to feed care-recipients made care-recipient disability and vulnerability overt; this was universally difficult for participants in this study to navigate. Participants reported using humour during mealtimes to de-emphasise the significance of dependence and enhance the protection of care-recipient dignity. Family carers use of humour was consistent with attempts to seek a positive in challenging mealtime situations:

> "We manage to make light of things as much as possible because I said to him (care-recipient) one day, you know when I was feeding him one day with the egg, 'If you're not nice, I'm going to hold it over here.'"… "I joke about it. 'Behave yourself or I'm going to hold the spoon over here ((laughing)).'" (Enid, Passage 154/166)

Most participants avoided social situations involving meals when care-recipients were dependent for feeding, given the embarrassment predicted to be associated with the inability of the care-recipient to eat and drink independently:

> "She (care-recipient) doesn't allow herself to be fed (.) at the table with others. So she would never allow me to feed her even a small piece of food." (Fran, Passage 102)

> "You can be sure that my Mum (care-recipient) wouldn't have been out and about and us feeding her."… "She wouldn't have had us feeding her in public. That wouldn't have happened. Or anything that made it obvious that my Mum was disabled." (Anthea, Passage 94/356)

5.2.2.2 Protecting the care-recipient from isolation and frustration

Family carers who were aware that care-recipients were withdrawing from social situations involving eating and drinking and were at risk of isolation endeavoured to protect care-recipients from this isolation by also withdrawing themselves:

> "I don't think I would like going off (to a family celebratory meal) and her (care-recipient) staying here. Who was going to do dinner for her? She would be eating on her own, no I wouldn't like that. No, no." (Carol, Passage 128)

Onset of care-recipient frustration associated with mealtimes initiated a protection-related response from family carers. In the context of feeding and swallowing difficulties, some participants described the frustration care-recipients experienced when opportunities for them to self-feed were compromised due to the reduced quality or availability of supports to facilitate this. This scenario often arose when formal carers were involved in mealtime management. Participants in this study gave examples of where formal carers had not applied (often time and resource-consuming) strategies, including meal set-up processes and specific feeding techniques, necessary to support independent self-feeding for care-recipients:

> "Once the pile is put in front of her (care-recipient), and we have an upturned cup right. So it's raised and there's a pile of six pieces and so on. Just lean forward and eat that and she manages that on her own. Now if it's not in the right place she can't eat it, so it has to be the right way, facing the right direction and all that. It's a skill but the carers need to know that or it just doesn't work. She spent a week in respite and they never managed to work it out and she didn't have any breakfast that week." (Fran, Passage 8)

5.2.2.3 Protecting the care-recipient from fear

In protecting the psycho-emotional status of the care-recipient, participants in this study described instances where they had engaged in emotional censorship to protect care-recipients from fear related to feeding and swallowing difficulties:

> "When somebody else is in trouble I tend to be very calm even though inside I'm dying. But I'm saying 'You'll be fine, you'll be fine, take it easy, just breathe, you'll be fine.'" (Enid, Passage 232)

Family carers described purposefully refraining from responding with alarm to negative sequalae associated with swallowing and self-feeding difficulties, in the moment as they were taking place, as this could lead to fear for the care-recipient:

> "He (care-recipient) seems to be able to get out of it (choking episode) himself. I don't get involved because I don't want to be causing anxiety. Too much pressure. That's the way we work it." (Gina, Passage 62)

> "If she (care-recipient) is choking, I would just stop and she knows if she needs anything I'm there but I don't have to do anything as I said. When she has been choking I have said to her 'In these situations is there anything I can do?' And really there isn't. It's one of those things, there's nothing anyone can do for you. You just have to get to grips with it yourself and you know, clean up and carry on."…"You try not to make an issue out of it (choking)." (Carol, Passage 84/176)

5.2.3 Protecting care-recipient dignity

The dignity of care-recipients was consistently foregrounded by family carers as being of paramount importance in feeding, swallowing and mealtime situations:

> "It kills you inside. It absolutely does. You can't imagine (feeding) your young husband you know. But you…-it's about preserving his dignity as much as we can. So you just do it. I've never done it before but I will. I just will, you know. And I'll deal with it in my own way you know." (Nonnie, Passage 108)

Participants in this study described navigating feeding, swallowing and mealtime situations in specific ways to protect and advocate for care-recipient dignity. Dignity was described in relation to dimensions including independence, autonomy, control, and choice. The ultimate responsibility to protect these aspects of dignity governed many family carer actions and interactions in the mealtime context and subsequently impacted family carer's experience of mealtimes.

5.2.3.1 Protecting independence and autonomy

Family carers prioritised care-recipient independence and protected care-recipient autonomy as part of their role and responsibility in supporting care-recipient feeding, swallowing and mealtime function:

> "It would be wrong of me to say I encourage her (care-recipient) (to eat), I don't have to. Sal knows, as I said. She is a very intelligent woman." (Peter, Passage 140)

Multiple examples of family carer protection of care-recipient autonomy were provided by participants with reference to feeding, swallowing and mealtime management:

> "No-one knows more about Connie's care than Connie does and she knows exactly how it needs to be done. How she likes her food and everything is something you got to know and learn and understand and just to give her that as a carer."… "That feeling that you still have control over yourself and your body and so on, what you can eat. They have to be the one to decide when all that changes. You can't force them to do something." (Fran, Passage 84/232-extended)

> "Give them (the care-recipient) space, allow them to manoeuvre around. Keep an eye on them if they need support and be there for them but at the same time they need to find their way because you can't chew or swallow for them." (Karen, Passage 214)

Participants in this study spoke of the importance of care-recipient autonomy in respect of care-recipient acceptance of adaptations, including aids and appliances, to facilitate independent feeding. Family carers were careful not to push their own preferences regarding the care-recipient's use of aids and appliances when they were problem solving solutions to the difficulties that care-recipients were experiencing, despite the potential for these difficulties to impact the family carer's own experience of feeding, swallowing and mealtime disability:

> "I did adapt a fork for Ian (care-recipient) at one point and it was in hospital because he didn't have me there to help him with different things. But the fork that I adapted he was saying when he got home 'Straighten that out, it reminds me of hospital.' I just bent it so it would come easier in this way (indicating towards the body)." … "I did get one knife from the medical place which has a great big fat handle but no he didn't want to use it (opting to be assisted to feed). So I have to adapt around him and what he can put up with. I'm gauging what is acceptable. What he is comfortable with." (Enid, Passage 242/246)

5.2.3.2 Protecting independence and the interface with formal care providers

Interactions with formal care providers presented an opportunity for participants to demonstrate the protection of care-recipient autonomy. Participants of this study described how they took care to protect care-recipient autonomy during exchanges with formal care providers, reducing or avoiding involvement by removing themselves from formal carer – care-recipient interactions at times:

> "She (speech and language therapist (SLT)) does speak to James (care-recipient) directly because he does prepare his own food. So I wouldn't be listening to anything that goes on down there." (Nonnie, Passage 174)

In exchanges with formal care providers, many participants in this study discussed actively "stepping back" from engaging in decision-making on aspects of care, which served as a mechanism for the protection of care-recipient autonomy. Family carers in this study also reported "stepping back" in respect of their attendance at healthcare appointments with the care-recipient, their evaluation of the quality of healthcare services being provided to the care-recipient and in the sharing of their opinion on the appropriateness of management strategies recommended by formal carers. Given the nature of this inquiry, feeding, swallowing and mealtime focussed interventions were foregrounded:

> "I leave it to her (care-recipient) to judge because she's in the best position to know what works for her so I certainly wouldn't be telling her…-well I have encouraged her to try it (thickening fluids), I did encourage her to try the tea but she said it was slimy ((laughing)) so fair enough. But liquids are obviously the most difficult thing because there's the least control with liquids."… "She still does like her tea. She has it and she does it at her own pace. She might only have a third of a cup or whatever but she does what feels good for her so I would let her decide if and how much liquid she wants to take in naturally without any thickener." (Carol, Passage 60)

> "We don't go by the book. So if you do go by the book and say 'Well James (care-recipient) it's better for you to have this in your coffee' is it going to cause a fight? Is it worth that coffee? My son has a science background and if the instruction manual said 'Take two of those in your coffee' he would put two of those in his coffee. He would. He wouldn't think outside the box. You know. If he was a carer, he would say 'But you must put these in your coffee.' Well he wouldn't do it because he would know I'd be cross with him. He would be concerned, he would say 'Shouldn't he be using this?' And I would say 'Yes. But just let him choose to himself.'" (Nonnie, Passage 218)

It was not uncommon for family carers in this study to "step back" from decision-making regarding gastrostomy feeding, despite, in many cases, having the sole responsibility for the management of the practical aspects of gastrostomy feeding. This could include the administration of gastrostomy feeds and problem solving gastrostomy feeding-related complications:

> "I let Rob (care-recipient) make the decision because he had his own intelligence at the time. And my daughter was with us and she probably told him the same 'Make your decision Dad and see how it goes.' And of course that's what we did."… "It was his decision, he made a decision, I can't make the decision." (Gina, Passage 26/18)

> "I said to James (care-recipient) 'Well what do you think of that (delaying gastrostomy)?' And James said 'Well what do you think of that?' And I said 'What do you think of that?' And James said 'I'm happy to leave it go.' And I said 'Well so am I.'" (Nonnie, Passage 168)

Protection of care-recipient dignity was linked to protection of care-recipient control and choice, the importance of which is presented next.

5.2.3.3 Protecting care-recipient control and choice

Protection of care-recipient dignity for the family carers in this study included protection of care-recipient control and choice in feeding, swallowing and mealtime related situations. Where possible, family carers reported that they advocated for and provided care-recipients with the opportunity to express their preference for how they wished to navigate choices regarding feeding and swallowing impairment. This included, but was not limited to, adherence to diet and fluid modifications, compensatory strategies, mealtime practicalities, and the care-recipient's ongoing ability to participate in roles, routines and rituals associated with mealtimes.

Participants frequently discussed care-recipient control and choice in relation to privacy. Given family carers differed from care-recipients at times in their preferences for privacy, when family carers were required to protect the privacy of the care-recipient to the extent where refusal of formal care occurred, the demands on family carers (including mealtime associated demands) could be impacted. By not including "others" in the management of the feeding, swallowing and mealtime consequences of MND, the availability of resources to support family carers in caring for their family members with MND could be restricted. Where differences in preference for privacy were noted amongst the members of the care dyad, participants commonly prioritised the privacy preferences of care-recipients over their own, to protect care-recipient autonomy. It was not uncommon for family carers to report that care-recipients requested family carers refrain from sharing details of the care-recipient's diagnosis and disability (including feeding and swallowing disability) with members of the extended family, neighbours and with people in the community, despite potential resource implications for family carers:

> "She (care-recipient) did her shopping every week. She did it. Now I'm doing it, getting the bits and pieces. Her own cousins would miss her and her own cousins I had to tell them 'Oh no she's fine, she's a problem with her mouth.' And as it got worse and worse and worse I started crying into their faces. They knew something was wrong." (Oliver, Passage 28)

At times, family carers shared the preferences of care-recipients to keep information regarding the illness and the associated disabilities (including feeding and swallowing) out of public view. Mike reported that he was cautious of the intentions of "others" when they were visiting his father, who had MND:

> "People that come when someone is sick, it's almost like nosing." (Mike, Passage 36)

Nonnie also expressed caution regarding who she would share information with within the context of a small community:

> "It depends whether I know they are genuine because we are a small community. Whether they have an illness in their own family, that changes everything. Like you are part of another family. Because they know inside (…) inside us we are all grieving." (Nonnie, Passage 82)

5.2.3.4 Infantilising as a specific threat to dignity

Family carers identified that feeding dependence and the requirement for modified consistency diets presented a specific threat to care-recipient dignity, referring to this on numerous occasions as infantilising. Participants with dependent children often overtly discussed the parallels between the care demands required of them in supporting care-recipients with MND-related feeding and swallowing difficulties and the care demands required of them to support children (particularly infants) with feeding and swallowing, highlighting the apparent similarities in the mealtime situations as particularly challenging:

> "I suppose I'm conscious that he (care-recipient) would have fed me ((tearing up)) (…) It's just, it's the circle of life. I don't know if circle of life is the right word. Just from doing (…) and him feeding me as a baby or whatever (…) But you don't…- I suppose not every family has to do it, or do they? Their father. You always expected them to (…) be there and just. That's just it really." …"The situation of having a baby and feeding one and feeding another (care-recipient)." (Mike, Passage 172/210)

Most participants actively sought to avoid or mitigate any risk of infantilising the care-recipient during mealtimes to protect their dignity. Family carers ensured that in presenting modified food they prepared for care-recipients they avoided or minimised the risk of any potential association with modified consistency diets provided to infants:

> "It's very finely chopped (modified pasta), and still like normal, you don't feel like you are getting a plate of baby food." (Carol, Passage 198)

In this study, participants gave many examples of where they had taken care to ensure that the terminology used to describe assisted feeding, swallowing and mealtime management was carefully delineated with the terminology frequently used in the context of feeding children and infants. Evidence was also provided where family carers demonstrated their endeavours to set an example to others to avoid infantilising as a potential threat to dignity:

> "He (care-recipient) would wear an apron, the food would drop down. He wasn't massively messy really but he could drop bits. When he was trying to eat."… "Mum went through a bit of a phase commenting on it as his bib…-which we and I always made a point of calling it his apron." (Una, Passage 18/20)

5.2.4 Protecting care-recipient quality of life

In this study, participants described many ways in which the QoL of the care-recipient was impacted by the presence of feeding and swallowing difficulties. The care-recipient's inability to self-feed and manage a full range of diet and fluid items without the use of strategies and supports was reported by participants to extensively impact care-recipient QoL. Participants in this study provided many examples of the attempts they had made to protect care-recipient QoL in the context of mealtimes, offering choices despite limitations and restrictions associated with care-recipient feeding and swallowing disability:

> "I've asked him (care-recipient) several times 'Is there something you would really love to have?' But he doesn't really." (Deirdre, Passage 196)

Family carers in this study prioritised care-recipient comfort and QoL when care-recipient self-feeding was observed to present as a "chore" which was "effortful" or "laborious". Family carers explained that the transition from care-recipient independent self-feeding appeared to be made easier for care-recipients when family carers planned and prepared meals that were naturally easier to manage, from both a self-feeding and swallowing perspective. Through family carer's efforts to make careful adjustments to diet and fluids, care-recipients were better able to retain function and remain included in mealtimes:

> "We've had birthdays and things like that and we tend to do them as we did before just be more conscious of what we are eating. That's all" (Deirdre, Passage 76).
>
> "I try to make suitable soft desserts because she (care-recipient) wouldn't be a big dessert person and then she will have a little one. I'd do fruit sauce and there's a particular vanilla yoghurt she likes, so I'll layer that if she only wants a little. I give her a small glass and I layer it up so it looks really pretty but it's very easy to eat." (Carol, Passage 88-extended)
>
> "I knew that my Mum's (care-recipient) arms were weak and I knew that it was laborious on her to have to cut up her food so we wanted to make it, the whole eating experience as easy as possible, just to get food into her. So if cutting up her food would make it easier eating then that's what we wanted to do." (Anthea, Passage 100)

The family carer's role included menu planning and shopping; ingredient preparation and cooking with specific regard to the method of cooking used; modification of diet prior to plating and on-the-plate; thickening fluids; planning individual seating positions, meal location and timing of the meal; table setting, including the set-up of modified cutlery and specialised plates and cups; ensuring availability of napkins, towels and tissues; physically assisting the care-recipient; and managing feeding and swallowing complications which could arise during the course of the meal. Despite the high demands associated with caring, being able to support care-recipients in their ability to remain engaged in eating and drinking-related routines and rituals was an important role of family carers protecting this aspect of mealtime normalcy.

5.2.4.1 Care-recipient quality of life, and the role of food and drink-related routines and rituals

Family carers endeavoured to protect care-recipient eating and drinking-related routines and rituals as an important component of care-recipient QoL. The importance of care-recipient food and drink-related routines and rituals in maintaining a normal sense of self for care-recipients was acknowledged by the participants in this study, who sought to support care-recipient's access to and inclusion in longstanding routines and rituals:

> "All her (care-recipient) married life Sarah (family member) came up here every Sunday and the two of them would have coffee in the kitchen. Sarah would come up and I would have to give her her coffee RIG (radiographically inserted gastrostomy). Because Sarah is having her coffee and she is having a coffee as

well. They would be chatting together, the two of them you know. She enjoyed those moments." (Oliver, Passage 158)

Participants recognised the importance of maintaining food and drink-related rituals for care-recipients despite the, at times, potentially high resource demand required of family carers to be able to facilitate this. In this study, family carers acknowledged the value of routines and rituals as extending beyond the moment:

> "It's what she (care-recipient) likes and she knows she can eat it and she has to get that in. There aren't any alternatives. So she has had the same breakfast for four or five years and that's it."… "Her day doesn't contain a hell of a whole lot. Life doesn't contain a hell of a whole lot so those very, very small things to you and I are actually what make up her daily routine and there's not a lot else beyond that." (Fran, Passage 74/76)

In this study, family carers discussed the traditional roles and routines of care-recipients which had been long established in relation to their planning, preparing and participating in meals within the family unit. Family carers protected mealtime normalcy for care-recipients by protecting the traditional food and drink-related roles of the care-recipient within the family unit. Care-recipients who were traditionally responsible for planning and preparing family meals were facilitated to continue to cook for their family with the support of family carers:

> "She (care-recipient) would still cook a meal, in fairness to her she would. She likes, she enjoys it, it would annoy her to see us not eat a meal in front of her and she has said that. She goes 'I want you still to eat.' For instance yesterday she went and she got a roast beef in SuperValu and she came home and cooked it for everyone. Because she wanted to. She enjoys being able to do the things she always did." (Hallie, Passage 148)

Another example of this was provided by Enid who described supporting her husband (care-recipient) to prepare foods in order to protect the sense of "normalcy" associated with the maintenance of his role as "cook":

> "He (care-recipient) can move things about on the pan and if he can't turn it then he will call me to turn it but he is in charge of it." (Enid, Passage 42)

Nonnie also reported supporting her husband (care-recipient) to plan and prepare meals, given that he had always invested great time and care in doing so for his family; cooking for the family was described as an important part of James's identity. Despite Nonnie's satisfaction that her husband was able to continue cooking for the family, Nonnie

remained apprehensive regarding the potential for future deterioration in function to disrupt these routines and rituals:

> "When James (care-recipient) can't eat (…) real food it's a huge concern for me. Because the sense of ceremony. He starts on a Thursday 'What are we going to feed our children?' I'm looking at him thinking 'What do you mean? I'm busy over the weekend. I don't care what you cook for them, they are all adults.' But that's him." (Nonnie, Passage 148)

In this study, family carers described supporting care-recipients to continue normal food and drink-related roles, responsibilities, routines and rituals as long as possible. With the progression of the illness, this could become more of a challenge, and despite all efforts to prioritise family carer support to enable care-recipient's to continue these roles, family carers were inevitably required to "take over" these responsibilities:

> "He (care-recipient) would have done the cooking quite a bit, even when I retired because he likes his food and he likes it so. And I would say I've probably taken over the cooking completely in the last…-definitely in the last year." (Enid, Passage 30)

The "take over" of mealtime-associated roles and responsibilities was challenging. Care-recipients loss of the ability to complete identify-confirming tasks associated with mealtimes tended to feel to family carers as though the "essence of the person" they were caring for was also being lost:

> "I'd be thinking she was the one that always got my dinner and here I am now (preparing hers)." (Oliver, Passage 48)

5.3 Protecting the wider family unit: Maintaining social equilibrium

In this study, it was common for family carers to support care-recipients with feeding, swallowing and mealtime functioning in the presence of other members of the wider family unit, given other family members often resided with care dyads or were present with them for significant periods of time. When members of the wider family unit were routinely present with the care dyad, the family carer's enactment of protection underpinned action and interaction not only with the care-recipient but with members of the wider family unit. In the context of the wider family unit, family carers attempted to maintain social equilibrium:

> "The family is trying to be as normal as can be. You just have to be normal." (Lisa, Passage 114)

Family carer protection of other family members arose when members of the wider family unit were involved in providing care to care-recipients with feeding and swallowing difficulties and were responsible for the management of complications arising. Family carers orientated protection towards the health status of members of the wider family unit who were providing care to care-recipients given the extent of the physical and psycho-emotional challenges experience by these individuals as they provided care, an important component of which was the care provided to support feeding, swallowing and mealtime function:

> "We all make sure everybody gets a break, not only one person is left with 'Oh I'm Sile's carer'. It would be definitely a team effort, it will be everybody doing it. It's not fair for one person to have it all on them. It's not just physically challenging, it's emotionally challenging as well." (Iris, Passage 74-extended)

> "I would stay over here a lot now to be honest with you, especially the last little while. I like giving my Dad a bit of a break as well. Because I worry about him as well."… "We don't want him stressing out either and getting sick." (Hallie, Passage 68-extended/70)

> "It's about being strategic and not burdening everybody." (Enid, Passage 220)

When other members of the wider family unit were assisting the participant with supporting the feeding, swallowing and mealtime functioning of care-recipients, delegation of care tasks, including those required to support care-recipient feeding and swallowing, was possible. When care tasks could be shared, protection of pre-existing relationships with the care-recipient was enhanced as some family members were able to avoid care tasks which could otherwise threaten this relationship. In reference to his avoidance of delegating enteral feeding-related tasks to other family members, Oliver reported:

> "I only wanted her (care-recipient) sister here just to keep her company rather than helping with the daily chores." (Passage 166)

The presence of young children within the family unit tended to shift the focus of family carer protection away from other members of the wider family unit (including the care-recipient) to these children during feeding, swallowing and mealtime situations:

> "That protection of the kids became stronger as the disease progressed because it became so much more difficult."… "I was trying to protect them and keep them away." (Tony, Passage 112)

Specific endeavours were described by family carers as they undertook to minimise the impact of the care-recipient's feeding and swallowing disability on children who were present within the wider family unit. Nonnie discussed this in relation to the sensitivity required in information sharing, whereby the slow presentation of filtered information regarding the likely progression of the expected difficulties (including feeding and swallowing difficulties) took place with children in the family unit:

> "Letting our family (referring to children) know as much as they need to know." (Nonnie, Passage 224)

It was the typical preference for family carers to prevent young children from assisting the care-recipient to feed. Many family carers in this study were conscious of the emotional impact of care-recipient feeding dependency on young children within the wider family unit:

> "One of the lads (children of the care-recipient) did say to me recently, he said 'There was times where we were <u>praying</u> for you to come home because we didn't want to, because it was so difficult to do the feeding.'…If I came home and it wasn't done I wasn't going to get upset or complain because I knew how difficult it was. And I didn't want that…-that is not a memory you want as a child. Remembers feeding his mother (care-recipient) because she couldn't."…"It's not the <u>right thing</u> in life that a child should be feeding their mother I think." (Tony, Passage 60/62-extended)

Participants in this study described attempts they made to prevent members of the wider family unit (who were not designated carers) from taking on new roles and responsibilities associated with feeding, swallowing and mealtime-related care tasks and, where possible, participants assumed complete responsibility for these new roles themselves. Participants reported focusing on protecting the longstanding roles, relationships and sense of normalcy for members of the wider family unit to minimise the overall impact of the feeding, swallowing and mealtime challenges induced by MND on the family:

> "One of them (children of the care-recipient) is great and will ask can she help with the dinner, 'Can I peel?' she wants to. So you're not making her do it. You wouldn't go in and say 'Right'. If she doesn't want to do it, leave her not to do it. Because

> we are there to do it."… "We don't want them to feel they have to grow up or do anything different than what they are doing now." (Iris, Passage 120)

Protection of the social equilibrium associated with the mealtime experience within the wider family unit was enacted by family carers in numerous ways. In some instances, participants sought to destigmatise feeding dependence by encouraging other individuals (with the exception of the young children of the care-recipient) to assist the care-recipient with feeding:

> "He (care-recipient) will still have a bacardi and tonic because that's what he drinks. I bring it out and then I'll leave it there and then while I get the dinner I'd say (to a family member) 'You know if he wants another drop' (motions to assist). On weekends another family member comes around and I may go out and they watch sport together and it could be anything, lucozade, and I'll say 'Right, I'm leaving his drink there.' And he (family member) will say 'Do you want a drink?'" (Bonnie, Passage 148)

Participants highlighted conditions such as the care-recipient's acceptance of the illness, their view of disability and their desire to remain involved in the mealtime experience as important factors in their successful ability to destigmatise feeding dependence. By destigmatising feeding dependence family carers sought to maximise care-recipient inclusion, maintain social equilibrium and improve the mealtime experience.

Beyond providing care and support for members of the wider family unit in relation to their ability to overcome changes associated with care-recipient feeding and swallowing disability, participants in this study sought to protect members of the wider family unit from the consequences of feeding and swallowing impairment, including the impact of these consequences on shared mealtimes. Family carers attempted to minimise adverse events related to care-recipient feeding and swallowing impairment that could be experienced within the context of a family meal. This applied to the potential psycho-emotional consequences members of the wider family unit could experience which were associated with care-recipient feeding and swallowing disability:

> "It's hard with the kids (children of the care-recipient) because you want her (care-recipient) to obviously be doing as much as she can with the kids, and then the kids don't respond to you very well, they want their Mammy. So it's…-if the kids need a hand with eating and Sile is sitting there, she would be telling them what to do and this and that but I'd be feeding them, the physical work." (Iris, Passage 116)

Feeding and swallowing-related complications could occur for care-recipients during shared meals, and family carers reported being observant of the reactions of members of the wider family unit during mealtimes to mitigate any associated distress:

> "One or two times it got caught in her (care-recipient) throat. It wasn't nice at the Sunday dinner, and then you look around the table and all the heads are dropped down because it wasn't a nice picture for them (children of the care-recipient)." (Tony, Passage 32)

Even though forward planning was reported by family carers to be difficult, family carers often described educating family members to prepare them for the potential feeding and swallowing complications that might be encountered during shared meals, protecting all family members from any unnecessarily heightened emotional distress during these incidences:

> "I said to Chris (family carer's brother) 'Look, this is how he (care-recipient) eats, this is what happens. He will choke, don't overly 'Dad are you okay? Dad are you okay?' give him his space. If he's not okay, you'll be able to tell. He will go silent and he will be holding his neck.' I said 'That's when you call an ambulance, you know the number to call the ambulance if it's that bad.'" (Karen, Passage 218)

Participants spoke of attempts they made to protect family members when adverse complications associated with care-recipient feeding and swallowing impairment arose during a shared mealtime. Participants spoke of providing members of the wider family unit with reassurance during adverse events to allow these family members to modulate the emotional distress they were experiencing. The actions of family carers in these situations served to maintain a stable emotional context for all family members involved:

> "The others (wider family unit) were over on Sunday and we were having the tea and cake and she (care-recipient) did have the coughing and she left the table and she went over and a couple of them turned around and were saying 'Should we do something?' And I was saying 'No there isn't anything, leave her to resolve it.'" (Carol, Passage 172)

> "They (children of the care-recipient) will refer to me (during a choking episode) and it's hard to listen to their Dad (care-recipient) choking but they and we have chosen to make all this as comfortable for James (care-recipient) as possible. You know without someone having to get up and start crying and leaving the room." (Nonnie, Passage 34)

Participants reported debriefing members of the wider family unit, offering them reassurance following their witness to feeding and swallowing-related adverse events:

> "I wouldn't go to each of them individually (following a choking event). They might… -Niamh (care-recipient) might have gone to the loo after dinner and I would go out to them and say 'Look, lads are you okay? Any issues? You know why this is happening?' And they were fine you know. That was my approach." (Tony, Passage 92)

Family carers in this study spoke of care-recipient's preferences to avoid food and drink-related celebrations at times, given the difficulties they experienced with feeding and swallowing. Regardless of the care-recipient's preference, participants often described continuing to mark these occasions given their significance for other members of the wider family unit:

> "She (care-recipient) doesn't like celebrating, she doesn't like her birthday so (…) the kids (children of the care-recipient) will make cake, she can't eat it (…) She's not, she's not part of that celebration so the idea of that being built around a meal (…) You would have gone out for a birthday to a restaurant or whatever it was so that's not an option (…) But we still try to do that, we still have the cake and candles (…) But she won't ever eat it." (Fran, Passage 154)

Participants emphasised the importance of "keeping the family together" despite the difficulties they faced enacting this over shared mealtimes. The unique contribution of mealtime routines, which reinforced the sense of connection within the wider family unit, was frequently referenced by family carers. Although family routines often required alteration given the presence of the physical disability which impacted care-recipient feeding and swallowing, family carers were dedicated to making adjustments as appropriate to enable family routines to continue:

> "If we (wider family unit) are having pizza, we will have pizza in front of the TV with her (care-recipient), so she's there. She has her recliner chair, she has her portion she gets set up and she will have a slice of pizza, small pieces but she will have a small slice of pizza. And we can do that easily without necessarily, without it being inside the kitchen or at a table so that will transfer in to where she is." (Fran, Passage 158)

> "We (wider family unit) moved around the corner and ate on the sofa but we still didn't turn the television on so it was still a family mealtime. It was just that we were sat on the sofa and eating food on our laps not sat at the table. So I guess in

that sense yeah it did still preserve that kind of family mealtime but just moving it to make it possible to carry on." (Una, Passage 42)

"She (care-recipient) was cooking…-the last time she cooked it was for her Grandson. She always wanted to do that and we even had to wheel her out in the wheelchair to get to the cooker and she'd put on, when Robbie (Grandson) was here you know. She would insist on cooking what Robbie wanted (Oliver, Passage 52)

Despite the desire of family carers to protect the cohesion of the family during mealtimes, as the illness advanced, it was not always possible to continue shared family meals. At times when the resources to support the ongoing inclusion of the care-recipient tended to outweigh the need to protect the care-recipient, and an unavoidable separation of the PwMND from the wider family unit during mealtimes could result.

5.4 *Protecting* orientated towards the health status of self

The core category *protecting* in this study represents a central concept shared by family carers essential in the framing of family carer action and interaction within feeding, swallowing and mealtime experiences. Data in this study suggested that, given observation of care-recipient MND-induced feeding, swallowing and mealtime challenges, family carer conceptualisation of their role (and ultimately their sense of self) within mealtime situations required re-orientation. Consolidation of the family carer's traditional role as members of the family unit, with the new responsibility to provide care within feeding, swallowing and mealtime situations, took place and this ultimately shaped participant mealtime experience.

The previous sections (section 5.2 and section 5.3) presented findings consistent with the fundamental belief of family carers that they were obligated to protect the physical and psycho-emotional status of care-recipients as well as other family members present during mealtime events. This obligation extended to protection of traditional mealtime-based roles and responsibilities, given identity threats potentially induced by the presence of feeding, swallow and mealtime disability could impact normalcy within the family unit, and lead to distress.

The information in the sections that follow (section 5.4.1 and section 5.4.2) illustrate family carer protection of self as a specific component of the core category *protecting*. These sections identify family carer self-protection of physical and psycho-emotional status as relatively uncommon given family carers desire to prioritise care-recipient and wider family

unit member needs when protecting against the negative consequences of feeding, swallowing and mealtime disability. Family carer's desire to protect their own physical and psycho-emotional health status typically arose when there was a concern that their competence and capacity to continue to provide acceptable quality home-based care, including care to support feeding, swallowing and mealtime function, may otherwise be impacted.

Data presented in chapter four described the psycho-emotional landscape of the experience of feeding, swallowing and mealtime disability for family carers and outlined that the negative consequences of the feeding, swallowing and mealtime disability required *bearing, braving and persevering* as family carers coped with and adjusted to disabiity. Many intervening factors were identified as important in how family carers managed third-party disability of feeding, swallowing and mealtime functioning. Despite the insidious impact of the feeding, swallowing and mealtime-related challenges on family carers, data suggested family carers in this study deprioritised their own physical and psycho-emotional well-being when managing the feeding, swallowing and mealtime disability induced by MND. Data also suggested that family carer deprioritisation of self was global, reflecting how family carers navigated the illness experience broadly. The lens of focus for discussion of family carer's protection of self (as a carer in the sense of the whole illness rather than in relation to the specific feeding and swallowing disability) is broad; consistent with participants postulation that their experience of feeding, swallowing and mealtime disability could not be rendered down from the whole illness experience. This section therefore demonstrates protection of self, including the protection of the relationship with care recipients, as important components of the (global) desire of family carers to self-protect under certain circumstances and provides the reader with a base from which to understand how family carers operationalised protection in the context of feeding, swallowing and mealtime experiences.

5.4.1 Protecting the physical status of self

It was rare in this study for participants to mention changes to their own physical status in relation to the demands inherent in supporting PwMND in relation to the concurrent disabilities experienced, an important one of which was feeding, swallowing and mealtime disability. Of all the participants, most (n=13) made no mention of their own physical health at all when discussing the impact of their experience supporting a family member with feeding and swallowing difficulties as part of the illness profile in MND. Of those who mentioned negative physical health, the most commonly mentioned negative sequelae was a lack of sleep or sleep quality:

> "What happens is that I go to sleep for five hours and I wake up and I start making lists in my head ((laughing))." (Nonnie, Passage 84)

> "You wouldn't really get sleep during the night." (Anthea, Passage 38)

Fluctuations in weight were described by some of the participants. Family carers attributed weight gain to a lack of exercise and weight loss to stress, outlining that they had been required to divert their time away from self-care activities to meet the demands associated with caring for their family member with MND:

> "It's difficult getting that time to go out to get that bit of fresh air and exercise" (Bonnie, Passage 168)

Participants compromised meal preferences, consumed fortified foods they had prepared for care-recipients, ate highly processed or convenience foods given the associated time efficiency, and ate at irregular times as they prioritised care-recipient mealtimes:

> "I would make sure she (care-recipient) was fixed up first. Yeah, I would give her her breakfast when she could eat a little bit. Now anything I did for myself was after she was. And the same with dinner time I would give her her RIG feed and then I would go and have my dinner." (Oliver, Passage 44)

> "What it meant for <u>me</u> as the illness progressed, it was more me trying to have something that I could eat while I was feeding Niamh (care-recipient) so that I was trying to manage time, <u>always</u> trying to manage time."… "So breakfast for me was having ((laughing)) having a coffee, having a coffee and a fried egg and something, balancing it on my lap while I was trying to feed Niamh." (Tony, Passage 2)

For the most part, participants deprioritised their own physical health unless they had reached "breaking point" or were at risk of "burnout". Family carer ill health was generally accepted by the participants as part of the commitment they had given to enhancing the lives of their family member with MND and this included supporting care-recipients as required in the context of ongoing feeding, swallowing and mealtime changes:

> "I think as a carer that is what you do. You put yourself second." (Tony, Passage 48)

5.4.2 Protecting the psycho-emotional status of self

Just as family carers tended to deprioritise their own physical status to meet care needs of the care recipient, participants in this study also deprioritised their own psycho-emotional health:

> "We didn't really talk about how we felt about it (MND)."… "We weren't the victims here. Any emotions or sad feelings we were feeling were really secondary in comparison to what my Mum (care-recipient) ((becoming teary))…" (Anthea, Passage 312/314)

When family carers were at risk of what they considered to be a significant negative mental health outcome, they appeared more likely to self-protect. Nonnie discussed the emotional exhaustion she experienced and the actions she took to self-protect:

> "I had to set up a programme for myself. I had to say 'Right.' I took a rest every day. I'd say to James (care-recipient) 'Right, I'm gone. I don't care if President Obama walks through the door, I'm going for a rest. I'm not to be disturbed.' I would go and it would be for ten or twenty minutes but I would be sound asleep. I wouldn't hear it if the house burnt down. I was mentally exhausted." (Nonnie, Passage 242)

Participants in this study described strategies they used to protect their mental health given the ongoing challenges involved in caring for a family member with MND. Being able to access assistance, reassurance and knowledge from family members and friends, especially those with expertise or "insider information" on aspects of the illness (including feeding and swallowing difficulties) and how difficulties could be managed, was helpful in family carers' ability to manage the illness:

> "If I couldn't hear him (care-recipient) breathing (when eating and drinking) I'm fortunate. I have a friend up the road who is a nurse and she would be my first call." (Nonnie, Passage 44)

Participants spoke of the value of the support from formal care providers in optimising their ability to protect their own psycho-emotional status while managing this arduous illness:

> "They (Irish Motor Neurone Disease Association (IMNDA) nursing staff) tell me what's what. What's the best way to do things. That's all. Just the best way to do it. You have to listen to them. They are the ones that know. They know what they are talking about." (Lisa, Passage 110)

Being able to take time out to “detach” and “distract” themselves from the consequences of the illness, including those related to feeding, swallowing and mealtime disability, was key for many of the participants:

> “The dogs keep us (care dyad) distracted. They still have to be walked and fed regardless of what else is going on. They all have their little personalities. You have to have your interests in other things, you can’t become too absorbed in the medical issues that you are facing, you try to live as normal a life as you can. Try to keep things as normal as possible.” (Carol, Passage 194-extended)

It was not always possible for family carers to take a break from care duties given the chronic, relentless nature of the illness. The progressive intensification of the demands including the level of support required to optimise feeding, swallowing and mealtime functioning as the care-recipient’s status deteriorated over time meant that carers could become overwhelmed, especially in the later stages of the illness:

> “I suppose it can be a little bit overwhelming I suppose when it’s all…-you just might want to take a break for half an hour but there isn’t really that time you know.” (Mark, Passage 52)

As discussed in section 4.4.1, being able to *remain present in the moment* was fundamental to the protection of hope for family carers who were managing an often “all-consuming” illness. Carers sacrificed their own needs and wants on many occasions to provide care and support to both the care-recipient and other family members in the context of MND. While for the most part, participants in this study actively deprioritised their own needs to protect the needs of the care-recipient (particularly during feeding, swallowing and mealtime situations), family carers established supports and engaged in strategies to protect themselves from ill health when it was essential to their ability to continue to provide care.

5.4.3 Protecting the pre-existing relationship between the members of the care dyad

The presence of MND in the lives of the individuals within the care dyad caused a fundamental change to the power balance within the relationship, as one of the individuals became a *carer* and the other was *in need of care*. Many participants in this study emphasised that it was a challenge to delineate the longstanding relationship with the new care-based relationship, as was required at times when care-based decisions, including those regarding feeding, swallowing and mealtime function, were required. When

describing the navigation of differences in mealtime preferences amongst himself and the care-recipient Rory stated:

> "There is a very fine line between the relationships and the care." (Rory, Passage 124)

In this study, family carers described the physical, psycho-social and psycho-emotional changes care-recipients faced, and how care-recipients were forced to rely on family carers to assist with many aspects of life as these changes occurred. Participants described the evolution of their role as carers, from initially assisting in the maintenance of feeding and swallowing ability to later supporting and facilitating adjustments required to enable care-recipients to retain feeding and swallowing function. As the illness progressed and became severe, family carers described the "take over" of meal-based roles and responsibilities from care-recipients as they supported the complete physical dependence of care-recipients. Participants referenced numerous changes to their relationship with the care-recipient as the illness progressed but endeavoured to "conserve the relationship" which had long predated the illness:

> "We managed to keep it at least until those last two weeks that I was still his daughter." (Una, Passage 62)

5.4.3.1 Relationship quality as a factor influencing the ability to withstand relationship challenges in feeding, swallowing and mealtime disability

Participants universally emphasised the importance of the quality of their relationship with the care-recipient and sought to protect this relationship as far as possible. The success of the pre-existing relationship was important in how successful family carers were able to protect the relationships present within the care dyad as the illness progressed and the need for care, including the need for support with feeding, swallowing and mealtime management, intensified. For family carers, the quality of the relationship within the care dyad was dimensionalised by trust, respect, openness, and communication:

> "My mother (care-recipient) is sensible and calm. She always trusts we are doing our best. You put something like this (MND) on someone who is difficult anyway, well that is a completely different scenario where everything is a battle and a fight. The simplest thing would be a battle and a standoff." (Carol, Passage 206-extended)

If the relationship between the family carer and care-recipient had been difficult prior to diagnosis, the presence of MND appeared to magnify this for participants when undertaking the role of carer:

> "Our relationship was probably slightly strained to an extent. Now it would have been strained anyway. As close as I was to my Mum (care-recipient), I don't think I could have stayed with her in the same…-I couldn't have stayed with her for two three days at a time, we'd just get on each other's nerves like she'd tell me to not leave on lights and not leave dishes around, I just couldn't…-we just would have gotten a bit on each other's nerves so with that in the background and then you're caring for her as well it was an added level of pressure." (Anthea, Passage 110)

Participants in this study reported valuing not only their ability to trust care-recipients but also the care-recipients ability to trust them, referencing the importance of this trust in protecting the relationship as well as facilitating optimal care. Iris described the role of trust in reassuring her sister (care-recipient) that she was able to respond to illness-related complications and changes, such as those impacting feeding, swallowing and mealtimes, in a calm, measured way, without getting "over worried" or "over upset":

> "They (family members) would get a bit too ahead of themselves. I think she knows with me I'm a bit more rational, so I won't jump any guns or get too extreme too quickly."…"She trusts me. She knows that I'm a little bit more able for what comes, more me than many other people in my family would be." (Iris, Passage 66/72)

Family carers reported that they were conscious that their observations of feeding, swallowing and mealtime situations involving any adverse events experienced by the care-recipient were fair. They sought to advocate for care-recipient independence and autonomy and to avoid premature suggestions regarding the need for any adjustment to support care-recipient function (e.g., the indication for modified consistency diet), as these actions appeared protective of the relationship within the care dyad.

Family carers in this study had important input into care and management decisions which could significantly impact care-recipient access to, or ability to fulfil, their preferences for care. For the most part, family carers were purposeful in ensuring their voice was as objective as possible when providing advice and navigating care decisions, particularly if a conflict of interest on how to proceed could arise such as when a demand on the family carer could be reduced through a particular course of action (e.g., care-recipient withdrawal from family mealtimes). Transparency within the relationship between the family carer and care-recipient was important to family carers to enable them to input into this process competently.

Many family carers described the responsibility they felt to observe the care-recipient while eating and drinking to ensure safety but also to allow them to pre-empt and mitigate

any significant difficulty. Family carers in this study were sensitive to the implications of their watchfulness over care-recipients as this could result in tension within the care dyad:

> "My Dad (care-recipient) cooks his own dinner and everything, he's perfect but he just gets very frustrated when he knows you are aware and that you are keeping an eye on him. He's a very proud man so you really have to watch yourself." (Karen, Passage 22)

The family carers' watchfulness implied a potential inability for the care-recipient to function without supervision and support, and although family carers felt that it was a necessary part of their role as carers, they outlined the potential threat to the care-recipient this watchfulness could present. In many instances, family carers attempted to conceal the degree to which they were being watchful:

> "He (care-recipient) said (to a friend) 'Look I'm going to bed, I think you better go.' Or something like that and she (care-recipient's daughter) said 'Oh no, he's staying here until Mammy comes home.' He (care-recipient) said 'What?' So he said 'So now you got a babysitter while you are out?' ((smiling)). He copped on that I was getting someone to stay." (Quinn, Passage 46)

Family carers in this study reported instances where care-recipients would conceal symptoms of feeding and swallowing difficulty when they were aware they were being watched:

> "If we walk into the room he (care-recipient) silences himself and you can see he's trying not to cough but he needs to."…"It's the coughing and choking on things, he's much more comfortable doing that on his own." (Karen, Passage 26/158)

At times family carers described being aware that it was the care-recipient's preference for them not to be involved in certain aspects of care. This preference was respected by the family carers when they had the resources available to support flexibility with care task designation:

> "I think he tolerates the boys doing it (gastrostomy feeding) for him rather than me doing it for him…because he's male. That's it. And that is private." (Gina, Passage 34)

Family carer watchfulness could disempower care-recipients, therefore some family carers chose not to monitor certain aspects of care-recipient health (e.g., weight) and allowed HSCPs to take full responsibility for their surveillance. This not only reduced care-

recipient and family carer anxiety around certain aspects of care-recipient health but also helped to protect the relationship within the care dyad.

Family carers acknowledged features of their own personality and temperament that they felt contributed to the quality of the relationship within the care dyad, which appeared to be facilitative when seeking to protect the relationship. Participants identified that having an "easy-going" or "non-confrontational" nature, being "practical" or "solution-focused", having "emotional balance", and being naturally "positive" and "optimistic" were all character traits that were helpful when managing relationship changes forced through the presence of feeding and swallowing disability associated with MND.

5.4.3.2 The nature of the relationship as a factor influencing the family carer's ability to protect the relationship from challenges in feeding, swallowing and mealtime disability

The nature of the pre-existing relationship and specifically the power dynamic within the relationship between members of the care dyad was important to how family carers navigated their role as carers. This included how they protected the relationship with care-recipients while managing feeding and swallowing difficulties. When there was a significant power differential in the relationship predating the illness, adjustment of this relationship as forced by new care needs could be distressing for family carers. Participants who provided care to spouses often described the change in relationship following establishment as a carer as similar to a "separation". Young adult participants (aged 18 to 40 years) who provided care to parents with MND commonly reported experiencing relationship changes as a "role reversal":

> "He's (care-recipient) meant to be this big strong character that's meant to be there and take care of you and then it's like the role reversal. He can take care of himself but there are different aspects. He mightn't be able to do this and he mightn't be able to do that and I might find myself doing it. I still in my head 'But I'm his little girl.'" (Karen, Passage 204)

In this study, evidence suggested that attempts made by young adult carers to support parent care-recipients with aspects of feeding, swallowing and mealtime difficulties in the earlier stages of the illness were often met with resistance from the care-recipient:

> "(I was) always saying 'Look Mam (care-recipient) have something.' Or 'Did you have this? Did you have that? Did you eat this morning? Did you eat this afternoon?' And that probably wasn't helping the situation because my Mam is independent and she would say to you 'If I want to eat, I'll eat.'"…"I probably feel

bad as well, telling her what to do, she's me Mam and she probably feels like it should be the other way around." (Hallie, Passage 218/224)

Karen described being almost blocked from providing care for her father with MND, identifying her father's sense of pride as incompatible with his ability to accept care:

> "He (care-recipient) won't let me in (…) My boss is my Dad's best friend and my boss turns to me and tells me 'Oh your Dad said this (reporting symptoms)…' And it's absolutely shocking, things that my Dad would tell him I find so upsetting because my Dad wouldn't tell me because I know he is trying to protect me." … "I think it's just his manliness. I think it's like he is taking a blow to his masculinity if he's seen being vulnerable." (Karen, Passage 8/162)

Some of the young adult carers of parents with MND indicated that their parent with MND had expressed feeling as though they had failed at their job as a parent given the dependence they now had on their children:

> "I think she (care-recipient) felt embarrassed, I think she felt like a failure. I think she actually said those words, that she let us down." (Anthea, Passage 358)

When feeding dependence was unavoidable, young adult carers often described how their parent with MND would give them "full direction" on how they wanted to be fed. Young adult carers reported feeling obliged to follow the specific directions of care-recipients despite these directions having the potential to increase the demands on family carers during assisted feeding. Family carers reported following these directions to protect the power dynamic within the relationship despite the high burden of care:

> "She'd (care-recipient) want it done exactly her way. And if I didn't agree with that or I didn't think that was the right way to do it then there would be this conflict. Especially when I had maybe ten things to do, or loads of things that I needed to do and my Mum was in my eyes making things more difficult by specifying the way in which she wanted things done."…"I think that a lot of the time I would have got annoyed about the fact that I felt it was not necessary to do it this way and I felt that my Mum was making it more difficult and I would have got annoyed and said it. And I could have ended up in tears and she did on occasion."… "I did feel like she was a robot." (Anthea, Passage 180-190-extended)

> "He (care-recipient) would be very particular about how he wanted it you know. The amount on the spoon. Feck's sake."… "You were getting full instructions on how he wanted it too. Full instructions on how much salt and butter he wanted." (Mike, Passage 142/154)

Differences of opinion regarding the management of feeding and swallowing difficulties arose at times within care dyads. When there was a difference of opinion on how to manage feeding and swallowing difficulties, being in a child-parent relationship added complexity to this challenge. A greater threat to dignity appeared likely if young adult carers were reluctant to compromise to meet the needs of their parent with MND:

> "When I told her (care-recipient) at one point I wasn't going to do this (provide an unsafe food) then she told me 'If you don't do it then I'm going to get it myself.' She really would have wanted it. It was massive. And I remember standing going it's ten o'clock at night. And I was thinking will I ring somebody or what will I do? It was really difficult." (Anthea, Passage 246)

5.4.3.3 Shared challenges as a protective factor in relationship changes within the care dyad

Several participants reported sharing the experience of traumatic events with care-recipients in the past. Pre-existing coping mechanisms established to overcome these traumatic events were acknowledged for their benefit in managing the changes that faced the care dyad, including those impacting feeding, swallowing and mealtime experiences:

> "We (care dyad) have come through fire and brimstone in our lives. We survived all that and deaths in the family. We have a system of working." (Peter, Passage 134)

Family carers who had shared experiences with care-recipients in managing other chronic and progressive illnesses within the family, including one dyad who had experience of providing care to a family member with MND (John), appeared to be able to use this experience to their advantage in maintaining the traditional relationship. These experiences of shared hardship were reported by family carers to improve care-recipient insight into the position of family carers. Multiple participants in this study reported that they were living with diet restrictions and were required to adjust their own eating and drinking habits while supporting the care-recipient with theirs. Additionally, some family carers reported that they required physical assistance (on a temporary basis) to complete activities of daily living. These carers highlighted that experiencing their own need for care appeared to be beneficial in facilitating the care-recipient's acceptance of their own care needs as it moved the focus away from the disability associated with MND and highlighted a shared vulnerability or limitation:

> "My condition is helping him (care-recipient) because I can't eat steak either." (Quinn, Passage 80)

5.4.3.4 Reinforcing interpersonal connection through care dyad-shared food and drink routines and rituals

Despite the functional limitations to eating and drinking experienced by the care-recipients and the need for family carer assistance with feeding, traditional routines involving eating and drinking, when shared by the individuals in the care dyad, were acknowledged for their importance in reinforcing the interpersonal connection that pre-existed and was enduring the illness:

> "I am very, very pleased for Sally (care-recipient) that she can still do these things (cook). I came in here this morning. Sat where I normally sit. I had a couple of sausage sandwiches that she had fried." (Peter, Passage 73)

> "We (care dyad) have had wine with our dinner every night for forty years. Some things don't change and it's one of the few illnesses and the medications it's not. If you can enjoy it, enjoy it." (Deirdre, Passage 136)

> "We (care dyad) would sit down and I would have on a Saturday evening a bottle of wine and I would have cheese and crackers and I would give her a small one or two and she would have that." (Fran, Passage 128)

Being able to continue shared food and drink rituals which were long established within the relationship, promoted a sense of normalcy within the dyad and were highly valued by family carers, who, despite the challenges associated with caregiving in the context of feeding, swallowing and mealtime impairment, sought to ensure that such rituals could be maintained.

5.5 Conclusion

This chapter has presented the central concept framing family carer action and interaction in their experience of feeding, swallowing and mealtime experiences as the core category *protecting*. Family carers in this study were cognisant of the impact of feeding and swallowing difficulties on the physical, psycho-social and psycho-emotional status of the family member directly impacted by the illness as well as on family members within the family unit who were indirectly impacted. Family carers assumed the responsibility to *protect* all individuals present during feeding, swallowing and mealtime situations to mitigate the impact of disability in this area as they consolidated their caregiving role with the traditional role as members of the family unit in the context of MND-induced feeding and swallowing impairment, this shaped their own mealtime experiences. The feeding and swallowing impairment endured by the PwMND resulted in significant changes to the

psycho-social and psycho-emotional status of all individuals present during mealtimes. The presence of feeding, swallowing and mealtime difficulties associated with MND challenged family carers' relationship with care-recipients, and the specific nature of the relationship between the family carer and the care-recipient (pre-dating MND) impacted the participants' ability to provide support in the context of feeding, swallowing and mealtime challenges.

Family carers in this study sought to provide nutrition and hydration to care-recipients in a way that limited the threat of any negative consequence to safety, wellbeing, dignity and QoL, and attempted to do so while honouring the social value of eating and drinking. Care-recipient, wider family unit and family carer-centred conditions which influenced the prioritisation and focus of *protecting* for the participants in this study have been highlighted in this chapter, fostering an understanding of both the complexity of the experience for family carers and how these features may influence family carer behaviour. The next chapter presents the key strategies family carers in this study engaged in when seeking to protect care-recipients, the members of the wider family unit, and, where necessary, themselves, as they managed feeding, swallowing and mealtime-related difficulties secondary to MND.

Chapter Six

Watchful shepherding: The operationalisation of *protecting*

"I go very gently about it and diplomatically, and I use skills to get him to come on board rather than shoving it into him or saying 'Look you must do this, that's what you have to do.' I've never done that. I'd say 'Look, for your good, this is what you should do.' I try to, try to do that. But you need skills and you need -all my life I've been dealing with people and trying to get the best out of people. I'm trying to use that to keep everything I want to stay calm. It's less controversial." (Quinn, Passage 72)

6.1 Introduction

An understanding of *protecting* for family carers was integral to understanding the family carer experience of feeding and swallowing impairment for the participants in this study. Family carers' ability to protect was achieved through the use of multiple strategies which arose through ongoing surveillance and judgement of feeding, eating and drinking behaviours occurring in isolation as well as within the mealtime experience. The action and interactions of family carers served to guide care-recipients, facilitating and enhancing their safety, dignity and quality of life (QoL). Under specific conditions, a more active role was required as care provided became contingent on the balancing of multiple and, at times, conflicting needs of the individuals within the family unit. Participants in this study set boundaries and enforced limits in relation to feeding, swallowing and mealtime behaviours, "taking the lead" when required, in order to shepherd their family members through the advancing illness.

The research questions in this study sought understanding regarding how family carers negotiate mealtimes following the onset of feeding and swallowing difficulties for PwMND and an uncovering key processes that explain how family carers of PwMND engage in mealtimes with the family members in receipt of their care. This chapter identifies and explains the key strategies undertaken by family carers in this study as they operationalised *protecting* within feeding, swallowing and mealtime events and situations. The processes used by family carers following their *surveillance and judgement of feeding, swallowing and mealtime situations* included 1) problem solving, 2) balance and compromise, 3) gatekeeping, 4) communicating strategically, 5) change management, and 6) teamwork and leadership. In this study, the six strategies accounting for the action and interactions of carers were identified as categories arising from the *surveillance and judgement of feeding, swallowing and mealtime situations* under the broader category

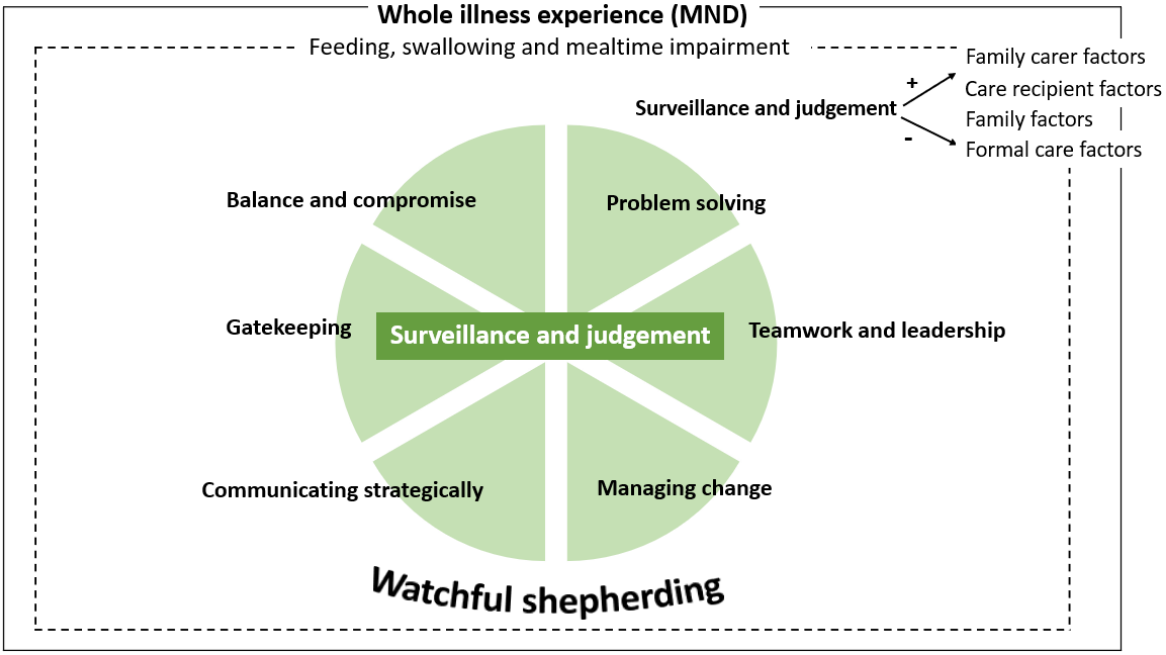
watchful shepherding. Data extracts are presented in this chapter to support the findings. Consistent with the previous findings chapters (chapter four and chapter five), these data extracts include transcription conventions, and the reader is directed to Appendix H for the full list of conventions used.

6.2 Surveillance and judgement of feeding and swallowing situations

Participants in this study described engaging in ongoing surveillance of feeding and swallowing situations as they were committed to assisting care-recipients with eating, drinking and mealtime difficulties. The functional consequences arising from Motor Neurone Disease (MND) were identified through continuous attention, not only to the impact difficulties were having on care-recipients, but also to the impact these difficulties were having on members of the wider family unit. The intensity of family carer surveillance was influenced by family carers' personal circumstances, care-recipient factors, family unit factors, and formal care factors (e.g., access to carer supports), as depicted in Figure 5 below.

Figure 5.

Key actions and interactions underpinning family carer operationalisation of care in the context of feeding, swallowing and mealtime challenges in MND



6.2.1 Problem solving: Building on skill set and seeking out expertise

In this study, family carers offered accounts of many situations where feeding, swallowing and mealtime difficulties warranted strategic management. Participants described often engaging in a process of trial and error as the physical limitations of the care-recipients, which gave rise to functional limitations, were problem-solved by family carers.

Carers discussed strategies they used to support care-recipients when care-recipients were faced with the need for diet and fluid modification. This often involved modifying food on the plate in the initial stages of the illness:

> "She (care-recipient) wouldn't be able to eat a full chip at once. I'd break them up for her and she'd eat them up. Fishcakes or whatever, cut them up very small. She was able to stick the fork in it and get it up to her mouth." (Steve, Passage 124)

More heavily modified diet consistencies were routinely required as the illness progressed. Family carers learned how to prepare food at the recommended consistencies and with consideration for the specific wishes and preferences of care-recipients:

> "It would have to be mushed up (…) and it couldn't be too hot, couldn't be too cold. Just to my Mum's (care-recipient) specifications." (Anthea, Passage 284)

> "I could see she (care-recipient) was having difficulty (with the meal). I said 'Why don't I just whizz it in the processor?' So I put the whole lot in the processor, gave it a couple of blasts to make it you know. And then she could eat the whole thing." (Carol, Passage 6)

> "I started using the Nutribullet towards the end. I would have been thinking 'Let's try this today and see what happens.'" (Tony, Passage 68)

Food preparation, once a modified consistency was required, involved a higher degree of planning and preparation:

> "I'm finding that meal planning is not a case of 'Okay, what's for dinner?' Looking in the fridge and realising you don't have anything suitable. There is more advanced thinking when you are shopping and looking at things." (Carol, Passage 14)

Family carers endeavoured to find foods that care-recipients enjoyed that were (without modification) the correct consistency for care-recipients to manage:

> "Choosing the right foods means that you don't have to do anything to them but other things you may need to do a lot of chopping to make sure they are…"… "Taking tablets now she (care-recipient) would have it in her yoghurt, She likes it in a bit of yoghurt. Or I would do an apple sauce and things like that are nice and the right thickness." (Carol, Passage 16/60-extended)

Providing foods that were naturally the correct consistency for care-recipients to manage (i.e., not in need of any further modification) was reported to have the potential to enhance care-recipient inclusion at mealtimes. When foods that were naturally the consistency recommended for care-recipients were able to be provided by family carers, it was not immediately obvious that care-recipients required something "special" or "separate" from other people present at the mealtime. The careful selection of food could therefore facilitate inclusion of the care-recipient at mealtimes. Bonnie referenced this in relation to menu planning for an upcoming celebration:

> "I'll try and do something we can all have" (Bonnie, Passage 140)

Family carers emphasised the importance of ensuring that multiple food options were available for care-recipients in the context of an unpredictable illness presentation. This enabled care-recipients to meet nutrition needs despite potential changes in the presentation of the illness, leading to variation in the care-recipient's ability to self-feed and swallow. Variation in care-recipient function was common and could arise due to changes in general medical status, the presence of an acute illness (e.g., co-occurring respiratory tract infection), medication changes and/or fatigue:

> "I always have two kinds of breads. So, I always have a bit of bread that is without the crusty part, you know one is more spongy so I always have that bread and then the other." (Rory, Passage 32)

> "I would always have something like bolognaise, soups, stews, I'd always have those available in the freezer."… "I find myself having to have things in the fridge like a cheesecake or a small tart or things which wouldn't have been on our diet at any stage." (Deirdre, Passage 10/12)

Not all participants had experience with modifying diet to support safe feeding prior to taking on the role of carer for their family member with MND. With the onset of care-recipient feeding and swallowing impairment, new skills in this area were required. The

safe modification of diet and fluids was one task where skill development was often guided by input from formal carers:

> "Through speaking with the dietitian who we were speaking to at the time she was giving us some ideas about things to do with food and it was a bit of a learning curve to…–even though I'm fairly good with food, it's what I'm working with but when you are dealing with someone who has a problem with eating which you're totally oblivious to it, that became more of a learning curve. I needed to understand a bit more about putting foods together and (…) just, even just mashing things up." (Bonnie, Passage 8)

Family carers whose role it had always been to plan and prepare meals and those who had specific skills in cooking often expressed a sense of contentedness and satisfaction that these skills could be used to assist care-recipients:

> "I was cooking all my life."… "We (care dyad) could eat <u>really much better</u> at home. We love food, we know how to cook, we love to cook." (Rory, Passage 4/94)

> "I'm a maniac for it anyways, for making food ((laughing))"… "If you open the fridge there, I would have the big dishes of carrots and I have my onions all done and my chicken. Sam (family carer's son) came in yesterday afternoon and said 'Mammy how many are you cooking for?'"… "Always, yeah. Always cooking." (Lisa, Passage 10-14)

Feeding difficulties were supported in numerous ways, as outlined by the participants in this study. For the most part, family carers sought to explore useful practical changes that would prolong independent feeding. Care-recipient head, neck, trunk, and upper limb weakness could be addressed with careful food positioning in some cases:

> "It matters whether it (chopped protein bar) is there (indicating the position of the upturned cup required to enable the care-recipient to self-feed) or there in front of her (care-recipient)." (Fran, Passage 82-extended)

Family carers were conscious of their own body position relative to the position of the person with MND (PwMND) during feeding to enable them to feed most effectively. Once the most effective feeding position was identified, this was used routinely:

> "It would have been always her on my left because I could never feed her sitting on my right. Little things like that became more of a routine once we figured it out." (Tony, Passage 2-extended)

Care-recipient fatigue was a factor that could impact feeding and swallowing safety and efficiency. Family carers in this study reported considering strategies to overcome care-recipient fatigue in order to maximise oral intake. These strategies addressed care-recipient fatigue systemically:

> "To have something a bit more useful in the middle of the day to be conscious of the fact that it is a better time for him (care-recipient) to eat so far as he's not tired." (Deirdre, Passage 6)

Methods to compensate for fatigue of the muscles required to enable care-recipients to self-feed were also considered by carers:

> "It's finding things he (care-recipient) can eat easily, that he can manipulate easy but that he wants to eat." (Enid, Passage 94)

> "She (care-recipient) was able to do a bit (feeding) for herself and then she would get tired and I would finish it off for her and give her the rest you know." (Steve, Passage 48)

Family carers at times encouraged care-recipients to use aids and appliances to support care-recipient independence and the safety and efficiency of eating. The use of these aids could reduce fatigue and improve care-recipient ability to sustain function, ultimately reducing the need for feeding assistance:

> "I gave him (care-recipient) a cup of tea but the mug was very heavy and there are lighter mugs in the house. So we just changed it over to another mug and the shape of it was easier for him to hold."… "He can still lift the cup. He uses the straw in the big heavy bottle because it's too heavy for him and it's easier to access it that way. And if I was trying…-because I can't sit up in the bed if he's having a drink in the middle of the night, I'm more likely to spill it over him. And what we have discovered is, pop this (straw) in and I can hold the bottle and then he can drink out of it at night and he gets a drink." (Enid, Passage 22/248)

> "They (beaker with lid) have been a godsend. I said 'Can I have one?' and they (hospital staff) said 'Oh alright then.' And since then I've beg, borrowed and stolen wherever I can get them." (Bonnie, Passage 160)

> "She (care-recipient) has her tea in a thermal. She has a small cup of tea." (Rory, Passage 70)

Family carers referenced the experience and knowledge they gained in providing care to their family member with MND and the extensive "learning curve" that they had engaged with while problem solving feeding, swallowing and mealtime-related difficulties:

> "Twelve months ago that (gastrostomy feeding) would have been a whole new concept and it's quite a big thing to get your head around. And the difference between gastrostomy and the NG (nasogastric) tube and the options there." (Una, Passage 48)

Family carers reported that their confidence in caring in the context of feeding and swallowing impairment increased via the training and support offered by formal care providers. The value of access to carer specific supports within the wider team of individuals managing feeding and swallowing difficulties was often highlighted by the participants in this study:

> "You try and find out as much as you can, pay attention when you are in clinic." (Carol, Passage 194-extended)

Participants identified that the ability to remain solution-focused and inventive in problem solving feeding and swallowing difficulties was a powerful facilitator in their provision of care:

> "I approached it very practically in terms of 'How do we?' Rather than giving out about 'Oh the eating is worse.' That was going to happen, there was nothing we could do about it, so it was 'What can we do to make it easier? Can I do anything? Can I adjust something?' There was a lot of that going on. In my job I need to be very solution focused dealing with practical problems day to day. I try to fix things and improve things and I think that helped." (Tony, Passage 84-extended)

> "There is a way around everything. He (care-recipient) could have the starter, he could have the soup, he could mix around with the food and have the vegetables, and he could have two desserts." (Nonnie, Passage 120)

Family carer's capacity for problem solving appeared to relate, at least in part to, their access to resources. If family carers were unable to access sufficient resources to foster flexibility in overcoming problems, it was more likely that the resignation of care-recipient function would be expedited.

The rate of progression of illness impacted family carer's capacity for problem solving and was crucially important to the family carer's ability to effectively solve feeding and

swallowing difficulties. A fast rate of illness progression often did not allow time for family carers to thoroughly problem solve the difficulties care-recipients were experiencing or trial potential strategies. Strategies, if successful, may not have offered relief from complications for long, and each time a significant deterioration in care-recipient feeding and swallowing function occurred, a new process of care-recipient and family carer acceptance of the illness, the new status, and the need for further supports was necessary.

6.2.2 Balance and compromise

The experience of family carers in their provision of care was often permeated by competing needs and a requirement to multi-task. In this study, family carers balanced the needs of the care-recipient, the family unit, health and social care professionals (HSCPs), and themselves in the context of capacity limitations as they delivered care. As prioritisation and negotiation were unavoidable, participants in this study routinely deprioritised their own needs to support the needs of others. In relation to feeding and swallowing-related situations, family carers gave numerous examples of compromises they had made given limited time availability and high care burden; the lowering of meal planning and preparation standards were commonly shared examples:

> "Quality is just going to be ((shrugging)) because otherwise it's just going to get too much and too hard work the whole thing." (Bonnie, Passage 172)

> "You end up with TV dinners (ready-made) which she (care-recipient) would otherwise disapprove of ((laughing))." (Fran, Passage 159)

Family carers described balancing care-recipients' inability to tolerate a full range of diet and fluid items with the desire to prepare and provide care-recipients with high-quality, aesthetically pleasing foods:

> "I was buying the best quality mince and then he (care-recipient) couldn't eat it…I was buying really nice stuff that looked appealing but he just wasn't enjoying it." …"One day in Tescos I saw their basic meals thing which had this horribly <u>insipid</u> looking thing which looked like it was just goo, horrible sauce. So I thought I'll just get one of the little packs. He <u>so</u> enjoyed it." (Bonnie, Passage 54/56)

In instances where care-recipients were unable to eat and drink functionally but the preparation of food and the provision of nourishment to family members were considered to be integral to the care-recipient's sense of identity, family carers balanced their need to

facilitate care-recipient dignity by facilitating care-recipient engagement in menu planning and meal preparation routines. This occurred despite family carer's own emotional discomfort in eating meals that had been made by the care-recipient, which the care-recipient themselves could not enjoy:

> "I know my Mam (care-recipient) would feel worse if I was to sit there and not eat. That would upset her more. She wants the family to be as normal as we possibly can." (Hallie, Passage 190)

In the example above (Hallie, Passage 190), Hallie expressed her discomfort eating meals prepared by her mother, not only due to the effort it took for the care-recipient to achieve the task but also because the care-recipient was severely dysphagic, primarily gastrostomy fed, and was not able to participate in the mealtime herself.

Inclusion of all family members in mealtimes was important to family carers, who often put multiple strategies in place to support care-recipient inclusion despite the numerous barriers they faced. Family carers described balancing the need for all family members (including care-recipients) to be included in mealtimes with the need for mealtime-related normalcy. Mealtime normalcy was dimensionalised by features including the timing, location, and type of meal that could be consumed:

> "It was still a family mealtime, it was just that we were sat on the sofa and eating foods on our laps." (Steve, Passage 42)

Family carers tried to avoid any negative psycho-emotional impact they believed would be associated with preparing themselves a different meal when the care-recipient's ability to manage oral intake was significantly limited. Participants described balancing their own need for a nutritious meal when care-recipients required diets of modified consistency. This tended to be more apparent when care-recipients were consuming more heavily modified consistency diets (e.g., pureed foods):

> "I was still wanting that we could both eat together so I was compromising on what I was eating so that we were still eating the same thing and now we don't. We don't eat together anymore and we don't eat the same thing anymore." (Bonnie, Passage 72)

Family carers weighed up the risk to care-recipient safety, autonomy and the potential threat to the relationship within the care dyad when required to make decisions either supporting or refusing to support high-risk feeding. This could arise not only in the

advanced stages of the illness (which were typically less challenging in this respect), but at other times throughout the illness trajectory. High-risk feeding often warranted family carer balance and compromise, particularly when care-recipients were fully dependent for meal preparation and feeding:

> "Dealing with anyone you have to respect their rights as an individual but at the same time try to protect them from danger or harm so it's…-you just need to keep conscious of that and that the dignity of the person is important."… "Well obviously they (family carers) don't want them (care-recipients) to come to harm but they (family carers) don't want to deprive. If somebody really wants something and it's not life threatening, sure. But it's that balance." (Carol, Passage 200/206)

> "You would have to weigh it up dependent on how difficult it was for him (care-recipient) at the time. The swallowing." (Mike, Passage 108)

Family carers in this study described difficulties in balancing risk when neither food modification nor the risk of choking were preferable options:

> "I don't like doing it (cutting up the care-recipient's food in public) but I prefer to do that than to see him (care-recipient) choke." (Quinn, Passage 94)

The relationship between the family carer and the care-recipient was often prioritised when the aims and agendas of the individuals in the care dyad differed. Family carers often "stepped back" from select responsibilities associated with caring in the context of feeding and swallowing disability when attempting to balance conflicting agendas:

> "There would have been lots of issues about me saying 'Look you've got to eat' or 'You've got to get nourishment in' but I think I have become a bit more tolerant in that." (Bonnie, Passage 72-extended)

> "I didn't argue with her (care-recipient) on that one (care-recipient refusing to eat in public), even though I would have liked her to stay engaged socially for longer." (Fran, Passage 112)

For the most part, family carers were willing to await experience of a negative complication associated with feeding and swallowing prior to suggesting an adaptation, modification, or restriction; balancing safety with the QoL needs of care-recipients.

Participants in this study described balancing HSCP preferences with the preferences of care-recipients as family carers considered where and how to best focus their support and

encouragement. This was most often apparent in respect of speech and language therapy (SLT) recommendations for compensatory strategies including modified consistency food and drinks:

> "She (SLT) recommended them (thickened fluids) about three months ago. I'd say we haven't even replaced that tin (thickener), he is not using it."… "I just think that in life you have to pick your battles you know. I'm hopeful that he will come to that decision himself." (Nonnie, Passage 56/58)

> "Her (care-recipient's) speech and language therapist had given her powder to thicken (.) ((sighing)) very light liquids and I think we tried it with a glass of wine at one stage and ((laughing)) it's not the same. No, no you just can't do that, there's just no point." (Fran, Passage 146)

Protection of the relationship between the family carer and the care-recipient was the most frequent reason expressed by family carers to account for their failure to actively encourage strict adherence to SLT recommendations. Care dyads, for the most part, found formal care input valuable but also valued the flexibility afforded to apply recommendations in their own way, with respect to their own individual circumstances.

Family carers made judgements on the quality of formal care received by the care-recipient. Family carers either supported (and facilitated) ongoing engagement or disengagement with these services, balancing the benefit of the service with the burden required to engage with them. When a high burden associated with travelling to appointments was involved, family carers balanced the benefit with the cost to care-recipients prior to supporting either care-recipient attendance or non-attendance at healthcare appointments.

The level of family carer input into the management of feeding and swallowing impairment varied amongst the care dyads, as referenced by the participants in this study. Family carers often reduced their exertion of control over care-related situations to support care-recipients' sense of control over their bodies and their preferences for care. Tony discussed balancing needs when his wife with MND had preferences regarding her approach to eating and drinking which were different from his:

> "The person who has the illness is directing you (to provide high-risk foods). There has been so much taken away that you don't want to take that as well." (Tony, Passage 110)

Although Tony's example in the above passage (Passage 110) illustrated deprioritisation of his own needs, family carers in this study did not always relinquish control over feeding and swallowing-related situations. When there was a difference in opinion in relation to the privacy and the input of formal care providers, family carers who felt a sense of desperation on how to proceed with care in some cases reported having to "go against" the wishes of the care-recipient; seeking input and support from formal care providers to reduce their sense of overwhelm:

> "I was trying to make her (care-recipient) see sense, but she just wouldn't see sense."…"I tried to get through to her that I need, I need help. I said 'It's to help you Rose. It's not to help me it's to help you.' No but she wouldn't accept it. I think in the end she did but ((sighs))." (Oliver, Passage 146/148)

Protection of care-recipient privacy when family carers felt they needed to exchange information with HSCPs in order to proceed with particular care duties or make decisions in their role as family carers, was another example of where the care-recipient's needs could not always be prioritised above those of the family carer. Some family carers described going to extreme lengths to respect the wishes of the care-recipient while attempting to also meet their own needs. Family carers often acknowledged the sensitivity of HSCPs who were able to strategically and discreetly assist them when a difference of approach or preference for care had become apparent within the care dyad:

> "The speech and language was coming down here very often and she had…-any problems, the way we communicated was the kids would know and they would speak to Rachel (SLT) without me (in order to protect trust and uphold care-recipient preference for privacy). They would say 'Dad is having this problem' or 'How should we solve it?' They would speak to the Rachel (on behalf of the family carer) and she would come down." (Oliver, Passage 124)

6.2.3 Gatekeeping

Participants referenced setting boundaries and limits in order to overcome imminent threats to the safety, QoL, psycho-emotional status and/or psycho-social status of the care recipients. Actions family carers took with members of the family unit, HSCPs, people in the community and the care-recipients themselves were indicative of obliging boundaries and limits set as they acted as gatekeepers when managing feeding, swallowing and mealtime difficulties associated with MND.

Many participants in this study provided examples of gatekeeping by family carers to optimise opportunities for, or promote, person-centred care in the context of feeding, swallowing and mealtime challenges. Family carers, cognisant of care-recipients who were experiencing difficulty accepting the diagnosis and understanding the impact MND was likely to have, were motivated to enhance care-recipient awareness of their medical status and ensure care-recipients were able to make informed care decisions. Family carers demonstrated great sensitivity to care-recipient preferences for care, protecting care-recipient dignity, QoL and the relationship within the care dyad, despite at times navigating differing opinions on optimal management of feeding, swallowing and mealtime difficulties. However, instances where family carers were non-complicit with care-recipient preferences for care, instead defining clear boundaries on what was acceptable to them in their role as carers, were presented by the participants in this study. These situations, for the most part, related to care-recipient safety. Firm boundaries, when set by family carers, were typically set in the context of care-recipient eating and drinking at risk to their own safety and were often based on formal care provider recommendations for restrictions which had been confirmed by family carers as beneficial through their own observation of the care-recipient. Although the importance of care-recipient QoL was universally emphasised by family carers, evidence of family carer refusal to support or facilitate care-recipients in taking food and drink items which were requested by care-recipients but considered by family carers to be unsafe, was provided:

> "If it wasn't in his (care-recipient) interest I'd say 'No.' I don't have any trouble with that."…"If it's good for him, it's good for him. If it's not 'You're not getting it' ((laughing)). End of story. That's it. There's no other way around it." (Lisa, Passage 152/154)

Boundary setting related to food and fluid intake varied as the poignancy of the specific food and drink items involved varied. When food and drink-related routines and rituals were considered by family carers to reflect habitual or identity-linked behaviours, restrictions on the intake of these items appeared to be less likely to be enforced by family carers. Hallie referenced the personal meaning attached to food and drink items in highlighting her mother's inability to enjoy a glass of brandy:

> "It (MND) is taking away the good of everything. It's hard. It's taking who they are away from them." (Hallie, Passage 104)

Although no family carer in this study reported that the recipient of their care had been formally diagnosed with a co-occurring cognitive impairment, references were made by

family carers to care-recipient behaviours consistent with inhibition, aggression and absentmindedness which could impact care-recipient safety when eating and drinking:

> "While she (care-recipient) was getting the dinner ready she would be carving the meat and she'd pick at a bit of meat. As she has done in the past. And it was that actual time when I had to give her the back blows where she choked on a small bit of chicken. So I said 'Why did you do that? You know you can't eat it?' And she said 'Sometimes I just forget, when I'm doing stuff. I forget that I can't have something.'" (Hallie, Passage 28)

Watchfulness over "absentminded" care-recipients, consistent with ensuring care-recipients did not inadvertently swallow an unsafe food or fluid, was consistent with family carer gatekeeping:

> "We just had to make sure there was nothing like that (hard sweets) in the house." (Hallie, Passage 24)

Participants in this study became adept at gatekeeping the interactions of members of the family unit as well as friends of the care-recipient, facilitating protection of social equilibrium as well as care-recipient dignity. The privacy of the care-recipient was often ensured through family carer actions, particularly when care-recipients were experiencing difficulty communicating. Family carers reported screening phone calls and callers to the house and were careful with the type and amount of information they shared regarding the status of the care-recipient, including information regarding feeding and swallowing ability:

> "I had to tell them (visitors) that she (care-recipient) was sleeping. If they rang I had to tell them she was sleeping or that she was busy with the nurse and they knew that we were lying. And then she just didn't see them, she had no interest in seeing them."… "My Mum's wishes came first and I didn't want my Mum…-I would have liked it when my Mum would have got enjoyment out of seeing her friends. That would have been good because that would have been something that brought her happiness but it didn't. And I knew that by seeing them would have made her unhappy therefore that was my paramount concern. Although I didn't like lying to them I really didn't care that much."…"I actually didn't really care that much because it was more important that my Mum wasn't made unhappy by seeing them." (Anthea, Passage 262-266)

Mediation as a process interwoven with gatekeeping was undertaken by the participants in this study, co-occurring when family carers were required to balance the need to protect

care-recipient autonomy while respecting the value of other individuals involved in the management of the illness, including formal care providers. Family carers described facilitating care-recipients who either wanted or were refusing to attend healthcare appointments by acting as a proxy or informant. Anthea described this in supporting her mother (care-recipient) who did not wish to attend a face-to-face appointment with a medical consultant, and liaising with medical professionals on behalf of her mother in order to reduce care-recipient burden:

> "I wanted to reduce the stress on my Mum (care-recipient)." (Anthea, Passage 152)

Family carers in this study described interactions which took place with formal healthcare providers where they pushed for action when it was felt that not enough was being done to diagnose the issues (including those with eating and drinking) being experienced by the eventual recipient of their care:

> "The doctor was obnoxious. He said 'You've been coming to me for the last three or four years, if there was something wrong I would surely pick up on it. So then he said to Mark (care-recipient) 'Would you like me to refer you to a neurologist?' And I answered 'If that is the next step from here then we are going.'" (Deirdre, Passage 188)

> "He (doctor) says 'It could be four to six months before you can get a scan if you go ahead with the Health Board.' We came back to the house here and I says 'God, that's a long time.' I rung up and says to him 'If I go private how long will it take?' He says 'Leave it with me.' That was about eleven o'clock in the morning, so about four o'clock in the evening he rang me and says 'You have an appointment tomorrow at three o'clock.'" (Steve, Passage 2)

Participants in this study spoke of their ongoing advocacy for care-recipients when they felt HSCP input at various stages was substandard, continuing to gatekeep HSCP input throughout all stages of the illness:

> "It did take a family member to administer the team. There were a number of professionals involved but sometimes the links between them weren't always the best and I do think that if my Mum (care-recipient) hadn't have had family members who were going to oversee things, follow things up, communicate between HCPs (healthcare professionals), that things wouldn't have happened, that things would have fallen by the wayside." (Anthea, Passage 18)

> "The doctor said to me 'We will make you an appointment for her now, you'll be sent out a notification of it.' Six weeks, we were in the MND clinic and they had said there was no record of any appointment there. So that could have been handled a lot better and we are still waiting to hear. We've talked to one of the nurses and she said there's a three months waiting list. And I explained that there were six or seven weeks blocked there. She said she would try backdate it but it is a little bit frustrating." (Hallie, Passage 114)

Family carers reported being observant of HSCP-led information sharing with the care-recipient given the potential risk to care-recipient psycho-emotional status if too much information was provided too quickly. Family carers at times sought to ensure that care-recipients were not overloaded with information from HSCPs, that HSCPs were reasonable regarding how much information could be retained by care-recipients and that HSCPs were mindful of the need for care-recipients to take time to consider information shared prior to them being requested to make a meaningful contribution to decision-making on the basis of this information. Family carers described instances where they were required to prepare HSCPs in advance of contact with the PwMND to ensure HSCPs adopted a sensitive, individualised approach with care-recipients, and one which was based on the status of the moment:

> "Because we couldn't discuss it (illness-related complications including feeding and swallowing difficulties) with Rose (care-recipient) openly here with anybody it had to be all hush hush and they (family) would talk to them (HSCPs), any problem I had. Then they would come down and they would be careful. The medical staff would be advised in advance." (Oliver, Passage 126)

Family carers in this study also described gatekeeping their own behaviour regarding their reluctance to share how they felt about the illness, protecting the care-recipient from any potential threat to psycho-emotional status, which, in relation to their own need for emotional support, was considered unnecessary:

> "Ordinarily I would have went to Mum (care-recipient) for advice but I couldn't because I couldn't burden her with that as well." (Anthea, Passage 110-extended)

6.2.4 Communicating strategically

Participants in this study often described the onerous nature of interacting with care-recipients on aspects of the illness, taking much care to protect care-recipients from any negative outcomes that could be associated with care-based interactions. The sensitivity

required of family carers when communicating with care-recipients (regarding care needs) appeared to be influenced in part by family carer's perceptions of the care-recipient's acceptance of the illness and associated disability (including feeding and swallowing), and how well they were coping or adjusting. When family carers felt care-recipients were experiencing high levels of distress in relation to their diagnosis, family carers often limited overt references to the presence of the illness:

> "I never said to my Mum (care-recipient) 'You have Motor Neurone Disease.' And she never said to me 'I have it.' We never spoke about it." (Anthea, Passage 339)

> "You could not discuss her condition. No." (Oliver, Passage 24)

Family carers, for the most part, "followed the lead" of care-recipients in relation to aspects of the feeding and swallowing impairment they thought they could raise for discussion, taking care not to threaten the psycho-emotional status or comfort of the care-recipient as well as respecting long-established communication styles, even if this could have an impact on the family carer's focus of care:

> "I don't want to upset her (care-recipient) either so I would hold back. My Mum keeps a lot to herself, she is that type of person, she wouldn't tell you a whole lot about her feelings, she's strong. Very strong. But that would come into my head. Does it really upset her that she is sitting there not able to eat everything we are eating?" (Hallie, Passage 188)

As all participants in this study maintained watchfulness over care-recipients, early identification of new feeding and swallowing difficulties could occur. Participants often described feeling reluctant to point out difficulties they had observed or offer support they felt might be appropriate to assist care-recipients if they had observed feeding, swallowing and mealtime difficulties. For family carers, communicating their observations regarding care-recipient decline risked violating care-recipient psycho-emotional status and made overt the extent of their watchfulness. This could contribute to an altered balance of power within the relationship:

> "I had to wait until a point came where I could suggest that (diet modification). I didn't want to suggest it sooner than she (care-recipient) was able for. When she got to the point when it was becoming an issue for <u>her</u> then I could suggest we do this." (Carol, Passage 18)

> "Pointing out whether my Mum (care-recipient) should or shouldn't do something is an acknowledgement of another stage in the disease and it's not a pleasant thing to do." (Anthea, Passage 304)

Participants tended to seek confirmation of patterns of feeding and swallowing impairment prior to considering actions based on their observations of care-recipient difficulty. Family carers ensured that all factors that may be contributing to an observed feeding, swallowing or mealtime difficulty had been accounted for before resigning to the fact that the new difficulty that was identified reflected a fundamental progression of the illness and permanent functional limitation:

> "I'm just trying to determine patterns in the sense that if he's (care-recipient) sitting on the couch, how is he managing with his eating and drinking. If he's sitting upright at the table, how he is. (Karen, Passage 170-extended)

Observing feeding and swallowing deterioration in a tentative manner appeared to enable carers to demonstrate to care-recipients their ability to modulate emotions, offer a fair evaluation of care-related situations and remain optimistic and hopeful in the face of this progressive illness, all of which family carers felt were beneficial to the relationships within the care dyad, and the care-recipient's confidence in them as a carer.

The personality and temperament, as well as the longstanding communication styles of the individuals within the care unit, were identified by participants in this study as conditions influencing family carers' approach to discussions regarding care-recipient deterioration in feeding, swallowing and mealtime function. The exact nature of the risks associated with addressing or avoiding discussions that highlighted an observation of deterioration in care-recipient feeding or swallowing was crucial to the family carers' approach:

> "It depends on their personality so they know themselves you are only coming at them with the best intentions. Definitely give them a bit of space to do what they want to do but don't take too much away from them at once." (Iris, Passage 162-extended)

> "She (care-recipient) would go ballistic if you told her that (nutritional intake was minimal). If I said to her 'You ate nothing, you are not eating anything.'" (Oliver, Passage 14-extended)

Many carers described refraining from verbally offering to help care-recipients who were experiencing difficulties with self-feeding, swallowing and mealtime management. Family carers described the potential risk that their offers of help would be refused by care-recipients (even if help was needed), as accepting help could overtly highlight care-recipient vulnerability. For some family carers, "jumping in" to help the care-recipient with feeding, swallowing or mealtime-related tasks (without asking) meant the potential threat to care-recipient dignity by making overt the assumed need for assistance could be avoided:

> "I could be honest and say 'Look Rod (care-recipient), we don't want to leave you on your own. We are worried and I have someone just to come. You don't need to talk to them you can read the paper. Let them walk around the garden. Just to have somebody around.' But he will say 'I don't want that. Don't do that again.' So you have to (proceed without requesting permission)." (Quinn, Passage 48)

> "(I) spoke to her (care-recipient) when I needed to speak to her (about care) and I just did as much as I could without annoying her about it." (Anthea, Passage 154)

> "I'll do things and I won't tell her (care-recipient) because if I tell her she will say 'No, no, no.'" (Hallie, Passage 158)

> "I remember one day she (care-recipient) was taking her potatoes, just the small ones in the plastic ones (bag) and she was trying (gesturing struggling) to open the plastic and I just took it off her and just started to open it straight away." (Iris, Passage 8)

Family carers offers to help assist care-recipients who were demonstrating difficulty with feeding and swallowing-related tasks were delivered strategically to reduce potential threats to dignity:

> "I would ask her (care-recipient) permission (to modify food and drink) 'Will I…?'" (Carol, Passage 10- extended)

Family carers were strategic in their communication, attempting to avoid conflict when family carers and care-recipients differed in their opinions on how to proceed with the management of feeding and swallowing difficulties. Family carers who maintained open communication regarding their observations and perspectives on care could be met with resistance from care-recipients:

> "I raised things I was concerned about and it did feel like every week there was a mini battle." (Una, Passage 12)

Negotiation was often required of family carers to limit or avoid conflict:

> "You'd be saying 'No, could you do this? Could you eat something else or could we give you a thickened liquid?'"…"I know she (care-recipient) used to ask for biscuits and I used to feel very conflicted in that because I knew that biscuits were very dry and crumbly and it wasn't a very good idea so we…-I'd kind of say 'Well what about sponge and custard?' And I'd go off making this custard for her (…)." (Anthea, Passage 58-extended/66)

Participants endeavoured to support the autonomy of care-recipients despite differences of opinion and the need for them to negotiate care:

> "It was a fine line between persuading and manhandling." (Carol, Passage 200-extended)

Despite the universal sense of tragic loss when care-recipients became dependent for feeding, the onset of care-recipient feeding dependence was, for the most part, not considered by family carers as a situation warranting direct or overt discussion with care-recipients in order to manage:

> "I think it (feeding) just kind of happened quite naturally here because I was just here and my mother was doing something else. But it felt, I don't know. I suppose I didn't really, when I was doing it you are not really thinking about it I suppose. You just have to get on with it." (Mike, Passage 18)

> "I just did it (assisted feeding). There was no major discussion." (Tony, Passage 66)

> "I think it (assisted feeding) happened (…) naturally makes it sound like a happy experience but it happened as it needed to and I don't feel like there was a lot to talk about. And I don't think would have been anything to have gained by sitting down and saying 'Okay so I'm going to feed you now, what's your thoughts on that?' It was easier just to gloss over things and just to be kind of be… –just do it. There was no point in talking about it. What was going to be…-for us what was going to be gained? There wasn't going to be much gained from talking about it. For us (care dyad) it was going to be a solution to a problem and we just did it." (Anthea, Passage 176)

> "It's (assisted feeding) a first time and it's done and it will become a routine." (Deirdre, Passage 184)

Family carers identified formal caregivers as having a significant role in initiating and facilitating open communication around the illness and resultant disability (including feeding and swallowing) within care dyads. Formal carers were particularly valued by family carers for their role in mediating information sharing on highly sensitive topics within the care dyad, including discussion around the care-recipient's preferences for life-prolonging interventions and end-of-life (EoL) care. When family carers felt unable to initiate or participate in open, honest discussions with care-recipients, input from formal carers was often sought. Being able to avoid sensitive discussions appeared to enable participants to continue to foreground and verify the value of the relationship with their family member with MND (outside of the care dynamic), minimise the significance of their role as a carer, and diminish the care-recipient's sense that family carers would have an opinion on what they thought was best:

> "I didn't want to push it (conversation regarding enteral feeding as part of advance care planning) because I didn't want it to put a strain on our relationship."… "I remember saying to one of the MND nurses that could they mention it to my Mum (care-recipient) because I didn't want to be the one mentioning it." (Anthea, Passage 172/174)

> "I don't want to suggest (gastrostomy feeding) -to force anything on her." (Carol, Passage 72)

6.2.4.1 Change management and the role of health and social care professionals

For family carers, the management of change was a key component of being able to protect the psycho-emotional status of care-recipients who were faced with changes on an ongoing basis due to the progression of the illness. Family carers spoke specifically of the value of HSCPs in their ability to provide support to family carers, guide them through the uncertainty of the illness, and manage unavoidable changes. While some family carers (Gina, John and Lisa) had previous experience in the context of life-limiting and progressive illnesses (including supporting family members at the EoL), not all family carers had encountered an illness of this severity within their family unit. The experience of HSCPs, particularly in circumstances where family carers had no experience managing ill health, was highly valued:

> "There was no serious illness or sickness that anybody in our family had dealt with before so we didn't know what was…-whereas the professionals did, they knew what was happening and whatever was going to come along at whatever speed it was going to happen." (Tony, Passage 18)

Family carers described the value of the advice given by HSCPs on managing the incessant changes and losses associated with MND (including those associated with feeding, swallowing and mealtime difficulties), setting the tone to enhance acceptance and coping within the family unit:

> "I think they were aware that Mum and Dad (care-recipient) were resistant to the whole thing and the nurse did say to Dad 'Look, you can't fight Motor Neurone, you have to work with it.' That was one of the things that always stays in my head." (Una, Passage 44)

Family carers discussed benefiting from the experience of HSCPs who had knowledge and expertise working with PwMND, as they were able to make helpful suggestions for managing the difficulties care-recipients were experiencing. The skills of the HSCPs enabled family carers to better facilitate care-recipient acceptance and coping with changes to feeding, swallowing and mealtime function as the illness progressed. Practical suggestions made by HSCPs could represent "silver linings" for unwelcome changes and were generally considered to be helpful:

> "The nurse was here last week with her (care-recipient) and she was saying she had a client who has the same, bulbar, can't swallow. He misses rashers, bacon so he just sucks on them just to get the taste. I said 'Why don't you do stuff like that, with your favourite foods, just get your taste?'" (Hallie, Passage 96)

Decision-making around gastrostomy feeding was a process that some participants in this study indicated benefitted from the input of HSCPs given the significance of this change. While the degree of formal caregiver influence over the care-recipients decision varied, some family carers in this study reported that they were happy to be guided in full by formal care providers as to the best way to proceed:

> "Your doctors and consultants will decide that (whether gastrostomy feeding is appropriate to consider). They will know. I couldn't say I don't want her to have the PEG (percutaneous endoscopic gastrostomy) in. There would be no point in saying that because the PEG would be for health reasons." (John, Passage 78)

Family carers views of the role of formal health providers and the information presented by formal carers were important influences on how family carers managed the gastrostomy decision-making process, and subsequently impacted how family carers supported this potential change for care-recipients.

The resistance of care-recipients to change was commonly reported by the participants in this study. In presenting information regarding likely future changes (including to feeding and swallowing) to the care-recipient (required by family carers as they sought information from care-recipients for future care preferences), family carers typically maintained open communication, balanced positive and negative outcomes associated with the change expected for both members of the care dyad, and used available resources to facilitate care-recipient acceptance.

6.2.5 Teamwork and "taking the lead"

Participants explained the need for the care dyad to work as a team in order to best meet the shared goals of optimising the health and wellbeing status of the care-recipient, and minimising the impact of the illness. Although not always, often participants described formally affirming with the care-recipient the need to approach the illness together as a team:

> "That was what we (care dyad) had said in the beginning. We will just have to - it's us and it's our lives, it's not just you. Obviously it's him but I mean as in we're going to do this together (…) ((becoming tearful)). But obviously I'd just help in whatever way I could. So we said that all along that we would work it out together." (Bonnie, Passage 32)

Not all participants overtly referenced purposeful plans made with care-recipients to address illness-related changes (including those impacting feeding and swallowing) as a team, but for the most part, synergy within the dyads was inferred in the accounts of family carers when describing how the care dyad navigated the illness. Mutual protection and respect were often described by family carers as features of the working relationship within the care dyad, which served as a conduit for effective teamwork. The positive impact of acknowledging the value and importance of the care-recipient's ongoing contribution to the lives of the family carer and members of the wider family unit (despite limitations in their ability to fulfil traditional family roles) was often expressed.

Family carers' ability to remain open to feedback from care-recipients on the quality of the care they were providing, including care to support mealtime functioning, was one

personal characteristic described by participants as beneficial for cohesion within the dyad. Family carers expressed that this strengthened the care dyad's effectiveness as a team:

> "I just said to him (care-recipient) 'Look, if there's any bit (of texture modified diet prepared by the family carer) at all you feel you can't manage, basically spit it out.'" (Bonnie, Passage 96-extended)

Although not always the case, family carers who were married partners of the recipient of their care tended to report managing care-recipient feedback regarding their care to support feeding, swallowing and mealtime functioning with more ease than those care dyads in other relationship types (e.g., young adult carers providing care for parents).

Teamworking as a strategic process underpinning the actions and interactions of family carers in this study extended beyond the care dyad to include members of the wider family unit, particularly where care was administered by a team of family members. Within the wider care unit, family carers described using the strengths of other team members when organising resources and delegating tasks in order to enhance the quality of care:

> "My daughter was better educated than me. She read up about it and all. If there were ever any problems I used to say to my daughter 'You can answer that question.' Whatever the doctors of nurses were putting to us, she was better educated than me. I says 'You do the talking.'" (Steve, Passage 36)

The leadership of the care team (within the care dyad) was often reported as being fluid. Family carers described being cognisant of the potential disempowering of the care-recipient when care situations called for their leadership. This could impact the participant's overt expression of leadership:

> "It's a fine line between wanting to help and infantilising somebody." (Carol, Passage 10-extended)

According to the reports of participants, it was common for them to display their leadership role discretely in order to protect care-recipient dignity. Examples of this provided by the family carers included when family carers offered opinions on how the care-recipient was managing the complications of the illness with family members, friends, and people within the community. Family carers took the lead on problem-solving strategies they felt might be useful to facilitate care-recipient acceptance of illness-related changes including those to feeding, swallowing and mealtime function when changes were imminent:

> "He (care-recipient) still cooks their (children) dinners, he still lines up all their dinners. I say 'James (care-recipient) isn't bringing them in to you now, you go and get them.'" (Nonnie, Passage 100)

In some care dyads, active family carer leadership within the carer – care-recipient relationship involved a takeover of roles and, subsequently, a potential threat to the dignity of the care-recipient. When faced with the feeding and swallowing-related consequences of MND, participants were confronted with care issues that were unavoidable and that warranted family carer action and leadership. Family carers were required to judge what actions might be acceptable and what actions were not, and at times described having to make "tough calls" or have the "final say" in care-related decisions. Knowing when to take direction and when to take the lead appeared to be important for family carers as they engaged in team working:

> "If I would cook something he (care-recipient) would say 'I don't like that food.' But I would say 'It's nice and soft and it's good for you.' And I would put sauce on or put something on it and he would eat it and he would say 'I like that now.' (Quinn, Passage 22)

For family carers, remaining fair, practical, balanced, insightful and transparent (where possible) generally appeared to be facilitative of effective teamwork in the context of feeding, swallowing and mealtime challenges and were relied on by family carers as they supported care-recipients throughout the stages of the illness:

> "Definitely let them go at their own pace but don't be afraid to ask them questions about their speech, their swallowing, how they are getting on with different tasks at home. Ask them how they are feeling about it and what you could take off them that they don't really want to do anyway. So it can free up more time for them to be doing what they want to be doing. But not taking anything away from them too quickly." (Iris, Passage 168-extended)

6.3 Conclusion

In this chapter, the personal accounts of participants have been provided, which evidence the key strategies family carers used to enact protection in the dispensing of care to family members with MND-induced feeding and swallowing impairment. Problem solving, balance and compromise, gatekeeping, strategic communication, change management, and teamwork and leadership were strategic processes engaged in by the participants in order to *protect*. The operational strategies outlined in this chapter occurred concurrently

and overlapped, often requiring the support of the care-recipient, members of the wider family and formal care providers to optimise effectiveness. The exact nature of the surveillance and judgement of feeding and swallowing-related situations, as well as the intensity at which this watchfulness occurred, was influenced by the family carer's own personal factors as well as those of the care-recipient, family unit and formal carers who were involved in managing the illness.

The finding chapters have presented the data obtained through this investigation. The following chapters synthesise and situate these findings within the wider body of evidence on MND, and more specifically within the evidence base on family caregiving in the context of feeding, swallowing and mealtime impairment (chapter seven). The following chapters offer both implications for clinical practice (chapter eight) and for future research (chapter nine).

SECTION FOUR

DISCUSSION OF RESEARCH FINDINGS

Chapter Seven

Synthesis of findings

7.1 Introduction

The preceding three chapters presented findings arising from this study which explored the feeding, swallowing and mealtime experience for family carers of people with Motor Neurone Disease (PwMND) using a grounded theory (GT) approach (Corbin & Strauss, 2008/2015). Chapter four positioned the experience of feeding, swallowing and mealtime impairment within the broader illness-related context and demonstrated how the unique feeding, swallowing and mealtime situations and events for family carers both contribute to and are underpinned by this context. Chapter five presented the core category *protecting* and illustrated the explanatory power of this concept when considering family carer action and interaction in feeding, swallowing and mealtime situations. Chapter six illustrated how participants enacted *protecting* as they supported care-recipients who experience feeding, swallowing and mealtime difficulties as a consequence of Motor Neurone Disease (MND). This chapter (chapter seven) synthesises the information presented in the preceding three chapters and positions key findings within the wider body of research in the field. In explicating the main findings of this study, a nuanced awareness of the challenges encountered by family carers and how these challenges may be negotiated by family carers is possible.

7.2 Discussion of findings

7.2.1 Onset of feeding and swallowing impairment is transformative for family carers

The conceptual framework presented in the findings for this study identified a psycho-emotional context of feeding and swallowing difficulties which was embedded within and inseparable from the psycho-emotional context of the whole illness experience. Clear delineation of the psycho-emotional context relevant to eating, drinking and mealtime experiences from the broader illness-related experience is known to be a challenge for family carers of PwMND (Lisiecka et al., 2020), potentially reflective of the all-encompassing nature of the illness (Aoun et al., 2021). However, unique feeding, swallowing and mealtime-related demands, situations, and experiences were uncovered in this study, which informed this context.

Family carers in this study experienced a psycho-emotional transformation on onset of symptoms consistent with a potential neurodegenerative illness including swallowing changes. The immediate transformation of family carers was reinforced via continuous exposure to the illness-related complications of the person they cared for. The lives of both PwMND (Brown & Addington-Hall, 2008; Locock et al., 2009) and family carers (Aoun et al., 2021; Costa et al., 2021) are well understood to undergo transformation following the onset of MND. Findings for this study confirm that feeding and swallowing impairments may trigger the transformation which ultimately encompasses the lives of family carers.

Persistent existential uncertainty and unpredictability in the context of feeding, swallowing and mealtime changes in this study gave rise to family carers' urge to remain present particularly during eating and drinking events. Similar findings across other progressive neurological, acquired neurological and head and neck oncology cohorts have been reported (Mole et al., 2021; Robinson et al., 2022; Zeng et al., 2023), potentially indicating a universal desire of family carers of dysphagic individuals to protect. Tramonti and colleagues (2014) described the nature of MND family carers' existence as similar to being in a state of *permanent emergency*. Participants in the current study were found to be on high alert, unable to relax, and hypervigilant for emergent signs and signals during care-recipient eating and drinking which may indicate a potential call to action. Actions required of family carers primarily pertained to the potential immediate care needs of care-recipients but were also reported in relation to the needs of members of the wider family unit.

Family carer preoccupation with care-recipient surveillance has previously been described in the limited evidence base on family carers in the context of MND-related oropharyngeal dysphagia (Lisiecka et al., 2020). Surveillance for family carers enabled protection of care-recipient safety by reducing the risk of choking and enabling rapid intervention in the event of choking, in the study by Lisiecka and colleagues (2020). Surveillance was also considered by family carers to be necessary in order to ensure that nutritional intake was optimised given family carers foregrounded the prognostic association with malnutrition (Janse Van Mantgem et al., 2020; Ning et al., 2019). In the current study, the function of family carer watchfulness extended beyond the urge to protect care-recipient safety to include protection of care-recipient psycho-social and psycho-emotional status. Care-recipient psycho-emotional and psycho-social status could be threatened in numerous ways dependent on the extent of eating, drinking and mealtime difficulties, and on the visibility of the disability both within and beyond the family unit. Protection of the psycho-

emotional and psycho-social status of members of the wider family unit was also an emphasised purpose of family carer surveillance, given that the negative consequences of feeding and swallowing impairment could extend across the family unit. Through ongoing surveillance, family carers in the current study felt better positioned to preserve the dignity, autonomy, independence, and normalcy of care-recipients and maintain the social equilibrium of the wider family unit. Family carer watchfulness was not only confirmed as present but was identified as more or less intense, extensive, or overt dependent on the eating, drinking or mealtime situation itself, and on a complex combination of care-recipient, family carer and wider family unit factors. There is a current paucity of research investigating the dysphagia experiences of the wider family unit in adult oropharyngeal dysphagia, and further investigation of family unit functioning during mealtimes in the presence of feeding, swallowing and mealtime disability is indicated.

7.2.2 The unique psycho-emotional landscape associated with feeding and swallowing impairment in MND

The broad psycho-emotional impact of caregiving in MND is accessible in the literature and encompassed via terms such as caregiver burden, strain, distress and/or quality of life (QoL). Many studies focused on the psycho-emotional impact of caregiving have been published in the last decade and have been centred around the needs of the family unit given increased acknowledgement that palliative healthcare should be inclusive of family carers. It is well known that caring for family members with MND affects not only the physical but also the psychological wellbeing of individuals (Aoun et al., 2012; Conroy et al., 2021; de Wit et al., 2018; Pinho & Gonçalves, 2016; Schischilevskij et al., 2021). Numerous published studies document sadness, loss, fear, anger, frustration, and guilt as part of the illness experience for family carers of PwMND (Conroy et al., 2021; Gauthier et al., 2007; Hecht et al., 2003; Jenkinson et al., 2000; Kaub-Wittemer et al., 2003; McCluskey, 2007). However, studies specifically attempting to capture the impact of feeding and swallowing difficulties on family carers are limited and predominantly focused on family carer's experiences of non-oral feeding (Stavroulakis et al., 2016; Stavroulakis et al., 2014). Rangira and colleagues (2022), in a systematic review of the available evidence, found that family carers of individuals with swallowing difficulties of mixed aetiology can be at heightened risk of negative psycho-emotional consequences. Specific to family carers of people with head and neck oncology diagnoses, the findings of a recent systematic review and meta-synthesis of qualitative evidence conducted by Zeng and colleagues (2022) also documented significant psychological and emotional consequences. In the present study, many examples of family carer-consuming senses of sadness, loss, fear, anger, frustration, and guilt in response to the feeding, swallowing and

mealtime challenges arising from MND have been presented, signalling the highly relevant nature of considering oropharyngeal dysphagia and feeding difficulties for family carers in this context.

Family carer sadness in the current study, and in previously published evidence on the dysphagia experience for family carers of PwMND (Lisiecka, 2020), occurred naturally given witness to care-recipient decline in the ability to self-feed and swallow. Prolonged, awkward, or messy eating and drinking, as well as care-recipient reliance on compensatory strategies (including aids and appliances) to support independent oral intake, confronted family carers with the vulnerability of care-recipients. The loss of care-recipient ability to self-feed was often identified as having a profound impact on family carers who were unable to avoid the cognitive association between care-recipient feeding dependence and feeding in the context of dependent children. Consequently, in this study, careful navigation of feeding dependency was required by family carers who sought to protect care-recipient dignity. Sensitivity was also necessary to protect (as far as possible) the traditional power balance in relationships, predating the establishment of a caregiver – care-recipient dynamic, particularly in the instance of feeding dependence.

As witnessing the care-recipient's loss of ability to participate in food and drink-related rituals, considered by family carers as essential for QoL, identity, normalcy, and social inclusion, evoked great sadness, so too did the care-recipient's loss of ability to swallow without restriction, caution, or fear. For family carers providing support to care-recipients with advanced illness, realising that it would not be possible for care-recipients to sustain life without artificial nutrition was a pivotal moment in the illness experience. Similar moments have been identified in the dysphagia experience of family carers in advanced oncology (Hui-Lin & Ting, 2022). Penrod et al. (2012) outlines that exposure to pivotal moments such as these can impact family carer progression through stages of coping (e.g., forcing family carer acknowledgement of the certainty of their family member's death); the findings of the current study did not contradict this.

Family carers in the current study described their own eating, drinking and mealtime-based losses in the context of the care-recipient's altered feeding and swallowing ability and/or regimes. Adjustments were required of family carer behaviour when mealtimes changed from being an enjoyable experience to one that was endured as a chore involving both physical and time-based demands. In concordance with previously published findings (Rangira et al., 2022), mealtimes for family carers lost spontaneity and became rigid given increased requirements for careful menu planning and preparation. The time required for family carers to optimise the success of mealtimes for care-

recipients meant that social and self-care opportunities for family carers could be restricted. This study highlighted that under similar conditions family carers' ability to engage in their own food and drink-related rituals, important for maintaining their sense of identity, often required adjustment or resignation.

Fear of choking and of catastrophic choking-related outcome is a well-documented feature of the experience for family carers of PwMND (Anderson et al., 2012; Hadjikoutis et al., 2000; Neudert et al., 2001; Whitehead et al., 2012), and this fear is shared by family carers in the context of other progressive illnesses (e.g., Parkinson's disease (Miller et al., 2006)), perhaps an inevitable part of the dysphagia experience in illnesses with deteriorating trajectories. Family carers in the present study provided evidence of the negotiation of fear during mealtimes given observed choking episodes, anticipation of the onset of complications relating to choking and aspiration (including terminal choking events and respiratory tract infection), and the expectation that swallowing deterioration was imminent for the PwMND. Family carers reported that a lack of formal healthcare training on multiple aspects of informal caring, including how to support care-recipients with oral and non-oral methods of feeding and how to troubleshoot complications, could impact family carer self-confidence and heighten their fear. Consistent with findings of other studies (Lisiecka, 2021; Stavroulakis et al., 2016), the practicalities involved in enteral feeding could result in family carer apprehension when assisting the care-recipient during mealtimes.

The level of responsibility borne by family carers in assisting care-recipients to emotionally adjust to the illness and the series of inherent losses they faced (of which the loss of feeding and swallowing function were foregrounded in this study), as well as their responsibility to support care and make decisions on various aspects of the illness, was burdensome for family carers in this study. Contributing to decisions on the management of feeding and swallowing impairment, including adherence to food and drink-related safety recommendations and the potential role for artificial nutrition, exacerbated a complex array of emotions for the family carer. When there was an obvious misalignment in family carer and care-recipient expectations, intentions, or perspectives on feeding, swallowing and mealtime difficulties, the opportunity for distressing conflict could arise. The family carers' ability to cope with interpersonal conflict over food and drinks could be complicated by the involvement of health and social care professionals (HSCPs) in the care of the PwMND.

The presence of MND forced role changes which were apparent in mealtime contexts not only for family carers who provided physical assistance with feeding, but also for those

required to take over domestic tasks associated with the logistics of eating, drinking and shared mealtimes. Complex emotions including guilt could arise in these circumstances, as was identified in the current study. In other studies, such as those within the context of dementia (Mole et al., 2021), when domestic roles such as menu planning, food shopping, meal preparation and modification were the traditional responsibilities of the individual family carer, the burden associated with these care tasks (which often demanded an increased level of resource from family carers due to the illness presence) could go unrecognised.

Mealtime changes in the current study were found to impact social roles within the family unit. Family carers described occasions where they were required to assist young family members dependent for feeding (on behalf of the care-recipient) when care-recipient upper limb weakness restricted physical ability. Family carers were also required to mediate family discussions occurring during mealtimes for care-recipients when care-recipients were no longer able to speak, eat and drink at the same time. The takeover of mealtime-based responsibilities, which could be linked at times with care-recipient's ability to function as a parent, were extremely challenging for the members of the wider family unit, and were managed with varying levels of success. Particular vulnerability of young families effected by MND was illuminated as guilt associated with the exposure of young children in the home to both the illness and illness associated eating, drinking, and mealtime-related consequences was acutely experienced by this specific cohort of family carers.

Similar to other studies conducted in chronic and palliative illness (Davis et al., 2021; Namasivayam-MacDonald & Shune, 2020; Rangira et al., 2022; Shune & Namasivayam-MacDonald, 2020), this study confirmed that poor psycho-emotional outcomes in family carers can be confounded by the presence of care-recipient feeding and swallowing impairment. Given family carers of PwMND have a tendency to de-emphasise the challenges they experience (Costa et al., 2021), perhaps juxtaposing their own burden with the level of burden experienced by their family member whose life would certainly be limited by MND, the extent of family carer ill-health experienced in response to feeding, swallowing and mealtime difficulties may be hidden. Careful attention to family carer experienced psycho-emotional challenges in the context of feeding and swallowing disability is warranted.

7.2.3 The unique psycho-social landscape associated with feeding and swallowing impairment in MND

The psycho-social consequences of feeding, swallowing and mealtime difficulties for family carers are experienced on multiple levels. Consequences can occur as a direct result of illness-based care demands and evolution of identity to align with that of a carer (e.g., truncated social opportunities). Role changes forced by the illness also have psycho-social consequences for family carers given the relationship between the members of the care-dyad is altered. As care-recipients respond to their own illness-forced identity challenges, the traditional (family-based) relationship and the newly established caregiving relationship are negotiated by both members of the care dyad. In this study, the psycho-social changes experienced by family carers extended beyond the relationship within the care dyad to act on the social landscape present within the wider family unit. Entwined in the changes that occur between the family carer and the care-recipient, the takeover of family roles and the fulfilment of new responsibilities by the family carer could impact the social equilibrium within the family unit. Even more broadly than the wider family unit, the impact of feeding, swallowing and mealtime changes for family carers in this study appeared to extend to and influence how members of the family unit situated themselves within society more broadly.

7.2.3.1 Stigmatisation associated with feeding, swallowing and mealtime difficulties amongst care dyad members

Oropharyngeal dysphagia (across aetiologies) has been known to impact socialisation within and outside of the family unit, affecting mealtime normalcy, family rituals and family dynamics (Dornan et al., 2021; Hui-Lin & Ting, 2022; Miller et al., 2006; Penner et al., 2012; Robinson et al., 2022; Zeng et al., 2023). A limited amount of research to date has attempted to explain these changes from the perspective of family carers of PwMND or carers of individuals with other progressive neurological illnesses (with the exception of broader investigations of mealtime changes for family carers of people with dementia). Similarly little evidence is available to indicate family-centred care management options for speech and language therapists (SLTs) who aim to improve the feeding and swallowing-associated (negative) psycho-social and psycho-emotional outcomes. Further research is required to guide the selection of suitable family-centred care management options for SLTs who aim to improve negative psycho-social and psycho-emotional outcomes associated with feeding and swallowing impairment.

Food and drinks are socially symbolic and are commonly associated with positive feelings of family, community, and culture (McQuestion et al., 2011). The cooking and preparation

of meals are fundamental to our daily thinking and how we act and organise our lives (Meiselman, 2008). According to Mintz and Du Bois (2002), meals can be important in both the consolidation and separation of groups from one another and in some cultures, the sharing of meals as a mechanism for fostering trust amongst family members has long been identified (Richards, 1948). However, tension, poor communication and power struggles can also be seen at mealtimes which can make the mealtime a stressful event for some (Burgoyne & Clark, 1983). Eating, drinking and mealtimes can be understood to perform powerful functions and involve a set of behaviours that are standardised amongst the individuals involved (Mead, 1943). If there is any disruption in the ability to self-feed, eat or drink, difficulty conforming to mealtime behavioural standards can arise and this can lead to harmful interpretations of a condition and potential stigma for people with oropharyngeal dysphagia (Padilla et al., 2019; Miller et al., 2006).

Although social consequences of oropharyngeal dysphagia for PwMND and the wider population of people who experience dysphagia have been documented, very few have attempted to formally capture and characterise the extent and depth of stigmatisation associated with feeding and swallowing impairment (Padilla et al., 2019). Third-party (or "affiliate" as it is also termed) stigmatisation as a consequence of swallowing disorder in MND has not yet received focused research attention. Evidence presented in a recent Dutch study (Sommers-Spijkerman et al., 2023) has correlated enacted and felt stigma with bulbar symptoms more broadly for both care-recipients and family carers in MND. Evidence regarding the specific stigma attached to feeding dependency in progressive neurological illness has not been well defined. The findings of the present study provide multiple examples of stigma experienced by care-recipients (as reported from the perspective of family carers) relating to both feeding and swallowing difficulty, and of attempts made by family carers to protect care-recipients from potential shame, embarrassment and isolation which could occur due to stigmatisation (see section 5.2.2).

Participants provided examples of shame and embarrassment experienced by care-recipients as a consequence of MND-related self-feeding difficulties, which included messy and awkward eating; swallowing impairment, which included oral loss of food, drinks, and saliva; care-recipient reliance on heavily modified diet and fluids or on enteral feeding, and care-recipient use of adaptations to compensate for self-feeding and swallowing difficulties. Participants described observing responses of care-recipients to social eating and drinking situations which suggested care-recipients viewed their own feeding and swallowing difficulties as atypical and aberrant (see section 5.2.2.1). Evidence was also presented by family carers, which indicated care-recipient's belief that

others felt similar. Many participants reported positive experiences whereby restaurant and café staff catered to requests from care-recipients in respect of table positioning (to maximise privacy), menu options and menu modifications during shared meals in public, family carers reported that some care-recipients were intolerant of any part of their illness (including self-feeding and swallowing disability) being visible to any extent. This finding is consistent with literature describing stigmatised identity in chronic illness (Charmaz, 1983) and highlights the relevance of considering stigmatisation in the context of feeding, swallowing and mealtime disability for other chronic conditions.

As reported by the participants in this study, care-recipients withdrew from social situations involving eating and drinking for multiple reasons, such as the degree of planning necessary to support care-recipients. Illness unpredictability complicating the planning process where careful planning of meals was necessary to overcome both whole-body and feeding and swallowing specific sequelae, and fluctuations in mood and motivation were to name a few. This self-withdrawal of care-recipients from social situations appeared to have a profound impact on both family carers and on the family unit, commonly family carers also withdrew from social situations in solidarity with care-recipients and with the intention to avoid separation within the care dyad.

While family carers endeavoured to protect care-recipients from potential mealtime stigmatisation within and beyond the family unit, many also indicated a sense of their own inner conflict as they too felt aspects of care-recipient's feeding and swallowing disability (e.g., texture modified diets and adaptations) were substandard or difficult to accept (see section 4.2.1). Family carer discomfort with feeding and swallowing disability has been documented in MND (Lisiecka et al., 2020). Language used by family carers in reference to care-recipient's feeding and swallowing disability in this study often indicated concerns regarding a disease-related reduction of care-recipient self-identity given their feeding and swallowing disability. Strategies were used by both care-recipients and family carers to minimise the visibility of feeding and swallowing disabilities (see section 5.2.2.1) and these could ultimately impact access to a social network of resources for both. While family carers were protecting care-recipients from potential stigmatisation within and beyond the family unit, they also appeared to make attempts to limit and control any of their own behaviours that could contribute to care-recipient stigmatisation. Family carers acknowledged successful attempts made by themselves or other individuals within and outside the family unit to destigmatise feeding and swallowing difficulties (e.g., by emphasising feeding dependence as an opportunity to foster closeness and demonstrate support). Attempts made by others to destigmatise care-recipient feeding and swallowing

difficulties typically promoted positive outcomes for both members of the care dyad (see section 5.3), although the success of this appeared to be influenced by the care-recipient's conceptualisation of illness and disability and their ability to accept and cope with their illness.

Further research attention is required to highlight important factors influencing stigmatisation (both perceived and enacted) specifically relating to feeding and swallowing disability. Given that illness and disability conceptualisation can vary based on cultural parameters, Irish-based research is required. An awareness of factors influencing perceived stigmatisation may better equip SLTs to provide education and intervention aimed at addressing this potentially modifiable illness consequence, and this may serve to enhance social outcomes associated with feeding and swallowing complications in MND. Being able to support care dyads to remain engaged in social situations that fulfil important cultural, religious, and family functions has the potential to improve QoL for each of the members of the care dyad.

7.2.3.2 Normalcy and the personal meaning of food and drinks within the care dyad

Food is described as a tool for psychological, emotional, and spiritual transformation (Méndez-Montoya, 2012), significant in both reflecting and creating identity (Aktas-Polat & Polat, 2020). The importance of normalcy in relation to food and drinks, and in eating and drinking routines and rituals was universally conveyed by the participants in this study (see sections 5.2.4.1 and 5.4.3.4). The depth of meaning related to an individual's food choices has been documented by McQuestion and colleagues (2011), who outline the symbolic nature of food:

> "Social, cultural, religious and economic factors combined affect an individual's food choices and variety, the selection of favourite foods and preferences, as well as the meanings associated with food and eating." (p. 149)

Indeed, what we choose to eat and drink and how we choose to do so appears significant in reflecting who we are as individuals, as members of a family unit, and says something of our culture.

Restrictions on food and drink choices, forced by illness-related changes experienced by PwMND and subsequently experienced as a dimension of third-party disability for family carers in this study, impacted the symbolic representation of food and drink for family carers. Food and drinks were transformed from a source of enjoyment, comfort, connection, and a medium for the demonstration and celebration of the uniqueness of

self. Similar to the findings of Lisiecka et al. (2020), for participants in this study, food became a potential source of discomfort and danger and could be viewed simply as a mechanism for survival (e.g., when nutritional status was solely linked to prognosis). Altered or absent food and drink-related mealtime routines highlighted care-recipient disability and the disconnection that had taken place within the family unit. Food preparation for family carers became associated with burden rather than enjoyment given the logistical demands involved in oral and/or enteral feeding, care-recipient dependence on them for feeding, and given care-recipient reliance on family carer-supported compensatory and behavioural strategies. Family carers in this study generally maintained that the logistics of food preparation in the context of feeding and swallowing impairment were not as challenging as the emotional challenges associated with witnessing family members lose their ability to eat and drink independently. For the family carers of PwMND in this study, being able to demonstrate love, affection, dedication and commitment through the careful preparation and administration of meals, similar to family carers in other contexts (Hui-Lin & Ting, 2022; McQuestion et al., 2011; Nund et al., 2014b), was important. This speaks to the need for HSCPs to consider their role and priorities in supporting family carers of people within a wider dysphagic cohort who are forced to navigate this loss.

Normalcy is important in identity maintenance, and eating, drinking and mealtime routines and rituals represent an important avenue for the demonstration of normalcy. The meanings attached to food and drinks are central not only to our identity but also to our relationships with others (DeRenzo, 1997). In this study family carers demonstrated that eating, drinking and mealtime routines were not only fundamental for the expression of care-recipient identity, but they were also important for maintaining equilibrium and cohesion amongst members of the wider family unit (including the care dyad). Threats to the cohesion of family relationships could arise in the presence of feeding and swallowing difficulty when food and drink-related routines which were considered important within the family unit, could not be maintained. Family carers used multiple strategies to protect care-recipients, members of the wider family unit, and, at times, themselves from the threats to identity, normalcy, and QoL that either altered or absent food and drink-based rituals could present.

7.2.3.3 Identity and the family carer in the context of the mealtime

The fundamental role of family carers relative to the management of feeding, swallowing and mealtime changes in the context of MND in this study involved *protection* (see chapter five). Family carers maintained constant watchfulness over care-recipients in

order to prioritise the direction of this protection towards care-recipient health status, dimensionalised by physical and psycho-emotional health; dignity, dimensionalised by autonomy, control, and choice; and care-recipient QoL. Family carers used many strategies when enacting protection in respect of the care-recipient, the wider family unit and, at times, themselves (see chapter six). The new roles and responsibilities required of family carers given the illness-related changes within the family unit (including feeding, swallowing and mealtime changes), ultimately impacted family carer identity. Family carers in this study provided many examples of the attempts they made to consolidate their new identity as a caregiver (including their role as a case manager, care-recipient advocate, and care-recipient emotional support person) with their well-established identity. In their new role, family carers sought to be wanted and appreciated by care-recipients; expressing preferences to be seen as competent, loyal, kind, insightful, fair and, as far as possible, objective. With the evolution of this new identity for family carers, family carers remained fearful of negative care-recipient judgement and, in this study, provided many examples of self-sacrifices made to facilitate the best possible experience of the illness trajectory for care-recipients.

7.2.3.4 Relationship changes between the person with MND and the family carer: Parentification, infantilisation and separation

Family carers in this study became quiet leaders responsible for mitigating the impact of feeding and swallowing-related difficulties experienced by care-recipients through gatekeeping and mediating within a range of public and private situations. Family carers used careful problem solving and strategic communication, among other strategies, to balance and prioritise needs (see chapter six). Family carers perceived their new responsibility to survey and analyse care-recipient feeding, swallowing and mealtime situations as distinct from their traditional functions within the family unit. Together with the direct takeover of roles and responsibilities from care-recipients, this could cause a potential power shift within the relationship. Evidence in this study suggested that power shifts within the care dyad were akin to the process of parentification (Svanberg et al., 2011) particularly when young adult carers of parents with MND entered into a caregiving relationship. Not all participants were able to successfully negotiate this relationship change (e.g., Karen), and this could increase the tendency towards negative outcomes for family carers (e.g., feelings of rejection).

Infantilisation of care-recipients was carefully controlled for by family carers, particularly when they were vulnerable to co-occuring parentification (Svanberg et al., 2011). However, family carers within married dyads also carefully considered their behaviours in

light of the potential risk of care-recipient infantilisation, given family carers' desire to protect the traditional relationship. For participants who were providing care to spouses with MND, the evolution of the relationship within the care dyad with the progression of illness and functional decline was often likened to a separation. This loss of connectedness is understood to be a common concern for family carers who are caregiving in the context of chronic health problems (Keating & Eales, 2017). A reduced sense of companionship, intimacy, communication, and reciprocity in emotional support are known contributors to family carers' sense of separation from care-recipients (Keating & Eales, 2017). Family carers in this study, consciously made attempts to control the sense of separation they encountered through their actions and interactions and went to great lengths to support care-recipient inclusion in mealtimes and food and drink-related routines and rituals (see section 5.2.4.1), often continuing to support food and drink related routines and rituals until the multiple challenges to achieving this became insurmountable. Participants in relationships where the traditional power differential was not as vast (e.g., a sister providing care to her sister with MND), or where the demographic within the dyad was aligned with an established expectation of care (e.g., a middle-aged daughter providing care to an older mother with MND) did not appear as vulnerable to the relationship discordance caused by the need for and provision of care. Relationship changes in these situations presented as more akin to a "stepping in" of family carers and appeared less disruptive to the care dyad members.

7.2.4 Facilitators of, and barriers to, family carers in supporting the person with MND with feeding and swallowing difficulty

Findings in the present study account for challenges experienced by family carers in the context of feeding, swallowing and mealtime difficulties, identifying many family carer, care-recipient, and family unit factors that can act as facilitators or barriers in care. The exact nature of the physical and emotional demands associated with eating, drinking and mealtimes was crucial in shaping the family carer experience. Family carer-based factors such as age, baseline psycho-emotional status, access to family and community-based supports and self-perceptions regarding the quality of the care they provide, have previously been identified as enablers or obstacles in the experience of family carers (Creemers et al., 2016; de Wit et al., 2018). Findings from the present study expand on these factors, highlighting the family carer's view on disability, perspective on the role and value of the caregiving role, previous experience with chronic and/or palliative illness and previous exposure to feeding and swallowing difficulties as important influences on the care experience. Personality and temperament factors (including family carer natural tendency towards optimism), the ability for family carers to tolerate loss of control and

adapt in a context of uncertainty, their level of self-confidence and self-assurance all appeared to influence family carer wellbeing when managing feeding, swallowing and mealtime difficulties. As mentioned, family carers' ability to balance the new caregiving role with the traditional family role they fulfilled within the wider family unit were important in their experience.

Care-recipient-based facilitators and barriers to family carers in caregiving, including care-recipient age, illness duration, and degree of physical dysfunction, have also been found to directly impact the family carer experience (de Wit et al., 2018). In the present study, the degree of feeding dependency and level of swallowing impairment were factors to consider when attempting to understand the family carer experience. The rate of progression of MND and the trajectory of decline, the care-recipient's personality and temperament prior to the illness, and their ability to accept the illness and cope with the series of associated losses also appeared to be important influences on family carer experience. Many of these factors are specifically associated with MND, highlighting the importance of yielding illness-specific evidence to guide clinical practice.

Care dyad-specific factors could also present either enablers or obstacles in illness navigation, as was indicated in the findings of this study. The longstanding communication style, level of transparency and the nature and quality of the relationship between the members of the dyad had a fundamental impact on how family carers experienced feeding and swallowing-related complications. Access to shared strategies for coping, those that had been developed in historical periods of adversity and were common to both members of the care dyad, the degree of alignment of illness management goals between the individuals in the care dyad and the overall sense of cohesion within the care dyad also affected the experience of caregiving.

Family unit factors, including the degree of family cohesion and the flexibility and adaptability within the family unit appeared to be important in family carers' ability to adjust to feeding, swallowing and mealtime difficulties, consistent with family systems models of illness conceptualisation (e.g., Rolland, 1994) and family functioning (e.g., Bowen, 1978; Olson, 2000). The extent to which the business of the family is linked with eating, drinking and mealtime rituals, the degree of threat to social equilibrium within the family unit which could arise from feeding and swallowing-related changes, and accessibility to other family members (as an emotional and physical support) were also identified as important in shaping the context of family carers.

7.2.5 Coping for family carers as enabled through *remaining present in the moment*

In this study, family carers referenced a lack of choice in accepting the illness and its related consequences (of which feeding and swallowing were foregrounded) as consistent with the universal sense that care responsibilities required bearing, braving and persevering as family carers endured the illness alongside the care-recipient. The duty that family carers feel to persevere with caregiving in the context of oropharyngeal dysphagia related to other neurological conditions (e.g., Parkinson's disease and stroke) has been described in themes such as '*You do whatever it takes'* (Howells et al., 2021), potentially suggestive of a universal family carer experience of feeding, swallowing and mealtime impairment. In MND, *living in the moment* is a known strategy used by family carers to enable containment of the full impact of the illness and enable perseverance by uncomplicating, mitigating or reducing care demands to those apparent in the here and now (Centers, 2001; Costa et al., 2021; Gale, 2015; Greenaway et al., 2015; Olesen et al., 2022). In this study, actively limiting projection and visualisation of the illness trajectory was a mechanism central to coping for family carers as they provided care to care-recipients with feeding and swallowing difficulties. These processes may also be central to the experience of feeding, swallowing and mealtime disability for family carers of individuals with other progressive neurological or chronic conditions. From the perspective of PwMND, *living in the moment* has been identified in the literature as facilitative of coping in the context of feeding and swallowing-related changes (Coates et al., 2023; Lisiecka et al., 2021). Fanos et al. (2008) suggests that *living in the moment* may also be a strategy used by family carers to sustain hope when confronted with the illness. For family carers in this study, gradual familiarisation with the unremitting loss of care-recipient feeding and swallowing ability as the illness evolved, rather than a sudden, forced anticipation of disease progression (which could arise during interactions with formal healthcare providers), appeared to facilitate family carer acceptance and tolerance of the illness. Being able to *live in the moment* was helpful for family carers, particularly given the unpredictability and uncertainty associated with this illness. Unlike the findings of Locock and Brown (2010), unpredictability was not identified as a potential avenue for hope for the participants of this study. Unlike Locock and Brown's (2010) cohort, which aligned unpredictability with an opportunity to negate the certainty of deterioration, unpredictability presented an obstacle for carers in this study who were attempting to cope with a changeable illness. In the current study, unpredictability contributed to a heightened level of fear as deterioration could potentially occur rapidly.

7.2.6 The centrality of hope for family carers

Hope, for the participants in this study, was a universally positive concept and deemed by participants to be essential to operate in a caregiving role. Family carers reported that hope was necessary to bear the effects of care-recipients' illness. The concept of hope as a resource is well situated within much of the literature on life-threatening illness (Ezzy, 2000; Kwon, 2002; Poppe, 2020; Schaufel et al., 2011). References to hope and the role of hope for family carers can also be found in the evidence base reporting on the broad experience of caregivers in MND (Centers, 2001; Costa et al., 2021). The centrality of hope to family carers of PwMND, specifically within the domain of feeding and swallowing impairment, has not yet been documented.

Findings in this study suggested that hope may provide an avenue for family carers to demonstrate control. Hope appeared to be entwined with the process of setting goals for care (corresponding with "intentional hope" as discussed by Poppe (2020)), which was most often led by and orientated towards the care-recipients' wishes but at times could be orientated towards family carers wishes for themselves or for the wider family unit. HSCPs were important conduits for hope identified by the participants in this study, and HSCP-led interactions for goal setting could provide opportunities for hope to either be reinforced or threatened. HSCP initiation of pre-emptive care in the management of feeding and swallowing difficulties could violate family carer hope, and threats to hope arising from formal care interactions could also impact family carer's perceptions of service quality, and subsequently their engagement with HSCPs.

7.3 Conclusion

This chapter has synthesised key findings of this study to illustrate the psycho-emotional and psycho-social parameters of the experience of MND-specific feeding, swallowing and mealtime changes for family carers. In synthesising the findings, the extent of the role and relationship changes and challenges family carers are exposed to has been brought to light. Awareness regarding the existential experience of family carers enables formal carers to understand the nature of the demands inherent in the family carer role. Careful attention to the reality of family carers is crucial in order for formal care providers to optimise therapeutic relationships with these caregivers, to support family carers appropriately as they interface with care-recipients and members of the wider family unit, and to authentically validate the importance of family carers as vital members of the care team.

Chapter Eight

Clinical implications of the study findings

8.1 Introduction

The evidence presented in chapters four, five, and six illuminates the depth of the complexities and unrelenting challenges that can occur in family caregiving for people with Motor Neurone Disease (PwMND). When associated with feeding and swallowing disability, the magnitude of the consequences of the disability is often not visible, despite the extensive impact impairment of feeding and swallowing can have on family carers' health, wellbeing and quality of life (QoL). The findings of this study indicate that the psycho-emotional and psycho-social consequences of feeding and swallowing disability can be just as devastating, if not more so, than functional limitations of the illness which permeate the lives of family carers. This study advances current knowledge on third-party disability associated with oropharyngeal dysphagia in Motor Neurone Disease (MND), with an agenda to inform and improve healthcare provided to family carers. In accordance with the impetus to improve care, this chapter outlines recommendations which promote high-quality, individualised, inclusive and responsive family-centred care.

It should be noted that the chosen approach for this study (i.e., qualitative) limits universal generalisability. Indeed, the interpretivist epistemological stance taken by the researcher in this study rejects generalisability as a research goal, holding that multiple views and interpretations of the family carer mealtime experience may be valid, rather than one single reality. Grounded theory (GT) methodology (Corbin & Strauss, 2008/2015) calls for the presentation of findings in such a way as to allow for judgement regarding the relevance and applicability of the findings. The findings in this study provide an authentic, credible and dependable rendering of the mealtime experiences of the research participants, and the researcher has provided sufficient information in regards to the profile and context of the study participants for comparative purposes. Limitations in the transferability of the findings based on features of homogeneity in participant demographic (e.g., predominantly white, Irish, providing care to individuals without cognitive-behavioural impairment) and context (e.g., sampled from within a single healthcare system) are acknowledged; the influence of same will be addressed further in section 10.4. Ultimately, in this study the researcher was not seeking certainty in sample to population transferability but rather aimed to sensitise clinicians and researchers to new ideas and concepts applicable in the context of third-party disability in MND-induced dysphagia (Blumer, 1954).

Consistent with this, the conceptual framework presented as the end-product in this study centralises a sufficiently broad core category (i.e., *protecting*), useful to studying other populations. Key processes explaining how family carers engage with feeding, swallowing and mealtime situations in the context of MND-induced feeding and swallowing impairment have been identified, and various conditions under which enactment of *protecting* in the context of feeding, swallowing and mealtime situations have been interrogated. Although variation in family carer experience of feeding, swallowing and mealtime situations in the context of MND (both within and beyond the Irish context) is to be expected, many aspects of the mealtime experience for family carers identified in this study appear in national and international literature on MND, and additionally within progressive neurological and chronic illness literature. Nevertheless, the clinical implications discussed in this chapter are not proposed as representative or relevant for the entire population of family carers of people with MND-induced feeding, swallowing and mealtime challenges. Rather, these recommendations have been grounded in the data obtained with respect to the participants of this study. Further evaluation and adaptation of the conceptual framework derived from this study (i.e., development of formal theory) will be useful to support wider application across contexts in future.

8.2 Implications of the findings for speech and language therapy services

Numerous challenges were described by family carers in this study, occurring as they coordinated their role as carers with the roles of all relevant stakeholders involved in care. This study focused on the experience of feeding, swallowing and mealtime difficulties associated with MND from the perspective of family carers. Given speech and language therapists (SLTs) are the primary professionals responsible for the management of feeding and swallowing disability (Ashford et al., 2009; Kent, 2012), the following sections discuss key changes to the design and delivery of SLT services warranting consideration to better meet family carer needs.

8.2.1 Emphasis on a family-centred approach from the initiation of care

In this study, family carers emphasised the positive impact of health and social care professionals (HSCPs) who were considerate of the needs of the family unit. An approach that centres the needs of the family unit from the time of care initiation may therefore enhance family carers' experience of services. Family unit cohesion and access to social supports are important in enhancing coping and adaptation in the context of this illness (Aoun et al., 2013; Mockford et al., 2006). Reinforcement of the importance of family unit cohesion in navigating this illness may be beneficial at the time of diagnosis. Procedures

for referral to SLT, which include identification of all relevant family members who will likely be supporting PwMND with the provision of care in the home, may facilitate SLTs in positioning family carers as vital members of the care team from illness onset. This may also serve to facilitate cohesion among members of the care triad.

8.2.2 Commencement of speech and language therapy intervention in response to family carer and care-recipient perceived need

International guidelines on the management of MND (Andersen et al., 2012; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020), as well as published models for MND care (Hardiman et al., 2002), indicate that early healthcare intervention is beneficial for individuals with a diagnosis of MND. Findings in the present study indicate that providing choice to families regarding the timing of initial SLT contact may be appropriate. In the present study, family carers expressed a high level of overwhelm related to multiple services initiating care concurrently in the early stages post diagnosis. While early SLT evaluation may be helpful for families experiencing negative consequences associated with feeding, swallowing, and mealtime difficulties, in the absence of an immediate, overt clinical indication for SLT input, routine SLT involvement may be considered by family carers an unnecessary contributor to overwhelm.

Flexibility and choice for care dyads regarding the initiation of services may demonstrate that services are cognisant of and responsive to the acute loss of control associated with illness onset (Foley et al., 2014b). Family carers in this study verified their sense of loss of control permeated the whole illness trajectory. Delaying initial SLT contact until care dyads deem input to be necessary may reduce threats to family unit normalcy and the identity of the PwMND, and may help HSCPs demonstrate their awareness of the extent of the impact of diagnosis in the early stages of the illness (Alquati et al., 2022). Caution is required with reactive approaches to swallowing intervention, given some symptoms of oropharyngeal dysphagia are difficult to detect or “silent” and some consequences (including aspiration pneumonia) can take an extended length of time to manifest (Perry et al., 2022). However, by providing care dyads education on both the extent of the role of the SLT (i.e., integrating physiological, psycho-emotional and psycho-social aspects of disability management), and indications for making contact with SLT services, as well as by ensuring services are resourced to a level enabling SLTs the flexibility required to respond to the needs of the care dyad promptly, the centrality of holistic care may be foregrounded. For family carers coping with the diagnosis using a task-based approach (Lazarus & Folkman, 1984) (see section 8.4.2) the opportunity to ask questions regarding

the role of family carers and expectations of them at an initial referral triage and illness counselling consult may be beneficial.

8.2.3 Choice in speech and language therapy service delivery for family carers

For individuals with MND, domiciliary visits are routinely offered by HSCPs working within community-based services in both Ireland and internationally (Connolly et al., 2015; Lerum et al., 2017). The likely assumption underpinning this service design may be that access to home-based services reduces physical, time, and financial burdens otherwise associated with in-person clinic-based attendance for families impacted by MND (Haulman et al., 2020). However, SLTs should remain aware of the risk of threats to privacy and disruption in the normalcy of the home environment that home-based healthcare interventions can present (Dawson & Kristjanson, 2003; Kristjanson & Aoun, 2004). Where possible, a choice of service delivery models (i.e., clinic-based, domiciliary and/or telehealth) may facilitate privacy and preserve the integrity of the family home. These were important priorities voiced by family carers in this study (see sections 4.2.3.1, 5.2.3.3, and 6.2.2).

8.2.4 Flexibility in speech and language therapy intervention schedules

Rigid and time-bound schedules for healthcare interventions (e.g., routine review at three-monthly intervals) were identified by the participants of this study as a problematic feature of community-based healthcare services, perceived as catering to the operational demands of healthcare services rather than the needs of the care dyad. Although there are no evidence-based review protocols for primary and community care services published, reports of family carers in this study consistently indicated that routine interval review schedules were in place for HSCP input. Structuring SLT input for feeding and swallowing impairment at pre-planned intervals may be problematic for some care dyads; potentially implying a lack of flexibility in the capacity to respond to needs and increasing the tendency towards pre-emptive care through forward planning for potential deterioration in the period between SLT interventions. Illness-based factors such as the stage and trajectory of the illness, the coping and adjustment patterns within the care dyad, and the potential for clinically critical events such as care-recipient withdrawal from meal-based family celebrations to arise may better inform SLT intervention schedules. When planning a schedule for review, consideration given to all risks associated with feeding, swallowing and mealtime difficulties (e.g., physiological, psycho-emotional, and psycho-social) may best suit family carer needs. Less frequent SLT reviews may be indicated in the early stages of the illness if feeding, swallowing, and mealtime difficulties

are sub-clinical, and a higher frequency of SLT input might be appropriate in the mid-stage of the illness when disease-related changes intensify and the needs of the care dyad reflect these changes (Galvin et al., 2018). For some families, less involvement in the advanced stages may be indicated, depending on the preferences for care within the family unit. Schedules of care, whilst responsive to differences in symptom presentation, environmental contexts, nutritional preferences, resource, and support access, if lacking in attention to the psycho-emotional and psycho-social context, may fail to comprehensively respond to the needs of the members of the care dyad.

8.2.5 Direct family carer access to speech and language therapy services

HSCPs are urged to consider family carers as healthcare service users who are potentially at risk of negative health-related sequelae due to the demands inherent in the caregiving roles they undertake (Galvin et al., 2018). In this study, family carers felt that their needs were overlooked as, in many cases, they were unable to openly discuss the negative physical, psycho-emotional and psycho-social consequences of feeding, swallowing and mealtimes that they had witnessed in providing care to their family members. It is not unusual for family carers to have trouble communicating observations and concerns they have in relation to care-recipient status with HSCPs in the presence of care-recipients. This study provides evidence of this difficulty and indicates that direct family carer access to SLT services may be appropriate at times to enable the sharing of information family carers feel may be important for caregiving. However, the PwMND remains the primary service user, and as such, integrity in upholding care-recipient confidentiality is essential. Consent to information sharing must be obtained from the PwMND, consistent with the Data Protection Act (Government of Ireland, 2018), and this sharing of information may be appropriate only when professional judgement indicates that the best interests of the PwMND would be served in doing so. The availability of direct access to SLT services for family carers for the purposes of supporting care-recipient care and providing an opportunity for SLTs to address the direct psycho-emotional and psycho-social consequences of feeding, swallowing and mealtime impairments for family carers may optimise care outcomes for both family carers and the person they care for.

Information sharing is important amongst all members of the MND care team, of which family carers are considered a part (Shoesmith et al., 2020). Good information sharing can improve relationships and enable the integration of the team. SLTs seeking to facilitate information sharing with family carers should be cognisant of the high care burden family carers experience and the high information load. Given their burden of care,

and the possibly sensitive nature of family carer-led care-based discussion, SLTs may seek to optimise communication with family carers by accepting a wide range of methods of communication (e.g., email correspondence, text messaging, telephone, and face-to-face contact) as a standard with these service users. Attending to family carer accessibility may help SLTs project an openness to receive contact and may help support family carer engagement. Given the complex nature of the family carer role and the high level of support required from formal carers to enable family carers to fulfil the extensive home-based care responsibilities they undertake, ensuring sufficient clinical time is allocated to meet family carer's needs at all stages of the illness trajectory is necessary for SLTs to deliver high-quality care.

8.3 Optimising the therapeutic relationship between the family carer and health and social care professionals

Family carer perceptions regarding the quality of therapeutic relationships with HSCPs can influence their experience of care (Baker et al., 2024; Harris et al., 2018; Olesen et al., 2022; Peters et al., 2013). The literature explains that the optimal therapeutic relationship in MND care may be characterised as a "situated friendship" (p. 214) (Brown, 2003). Empathy, trust, active listening and collaboration have been identified as important features of therapeutic relationships which are aligned with the concept of situated friendships (Baker et al., 2024). Within the context of the broad illness experience, Olesen et al. (2022) report that the nature and quality of the HSCP - family unit interaction may significantly impact the family's ability to cope with the presence of the illness. Evidence obtained in this study (see section 4.2.5) confirms that the therapeutic relationships established in the multi-agent approach to management of feeding, swallowing and mealtime changes associated with MND are important in family carers perceptions of care quality. This study therefore confirms findings previously reported on therapeutic relationships (Harris et al., 2018; Olesen et al., 2022; Peters et al., 2013) and demonstrates important features of the relationships between SLTs (as well as other HSCPs) and family units which may be prioritised when establishing and maintaining rapport.

8.3.1 Embodying therapeutic qualities which enhance family carer engagement

Fourie (2009) described therapeutic qualities which appear to be facilitative of working relationships for individuals receiving SLT care, identifying that in many instances, it is not necessarily *what* is delivered in therapeutic exchanges but *how* therapeutic exchanges are delivered that is paramount. Evidence in the current study verifies the importance of relationship-based influencing factors, perhaps the most poignant of which was the SLT's

ability to enable or limit family carer hope. Similar to the findings of Fourie (2009), participants in this study identified that SLTs who were flexible, responsive, and attentive to the needs of both members of the care dyad; those who were trustworthy, knowledgeable, experienced, comprehensive and fair, promoted better outcomes amongst care dyad members when working together to address the feeding, swallowing and mealtime consequences of MND.

8.3.2 Acknowledging the burden of care

The well-documented psycho-emotional consequences experienced by family carers of PwMND (Aoun et al., 2013; Olesen et al., 2022; Pinho & Gonçalves, 2016; Schischlevskij et al., 2021; Siciliano et al., 2017) have been verified by the findings in this study (see chapter four). Echoing the sentiments of Conroy and colleagues (2021), family carers who were under high levels of stress given chronic, unremitting caregiving responsibilities, combined with resource limitations, were reluctant to foreground their own physical and psycho-emotional needs unless their levels of distress grew to levels prohibitive of the ability to provide care. In the present study, family carers' psycho-emotional status appeared to influence their coping style (e.g., task-orientated, avoidance-orientated or emotion-orientated (Endler & Parker, 1990; Lazarus & Folkman, 1984)), resonating with other evidence in the field (Siciliano et al., 2017). Family carer coping had widespread impacts on many aspects of care, including information sharing and decision-making in the context of feeding, swallowing and mealtime challenges. Care taken to prevent any unnecessary burden for family carers which could arise through SLT therapeutic exchanges (e.g., through expectations regarding family carer capacity to support the role of SLTs in the home) and to acknowledge the primacy of the relationship pre-dating the care relationship may improve outcomes and enhance the relationship between SLTs and family carers. The most recent clinical guidelines on MND (MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020) acknowledge the potential role for family carer-centred supports, such as support groups, counselling and other psychologically targeted interventions to address the psycho-emotional consequences of the family carer experience. SLTs may help to mitigate family carer burden by attuning to the psycho-emotional experience of caring in the context of feeding, swallowing and mealtime difficulties. Strategies such as purposefully eliciting family carer narratives in strategic clinical interviews (given the absence of formalised screening processes), dedicating time to meet the needs of family carers as they arise relative to SLT practice, discussing goals shared by the members of the family unit, and ensuring a comprehensive package of information is available regarding supports available to support family carer wellbeing may be helpful.

8.3.3 Acknowledging family carers as experts through their experience of caring for the person with MND

Being attuned to the significant role family carers take on in managing all aspects of the illness, including the management of feeding, swallowing and mealtime difficulties, may facilitate SLTs who wish to convey the value of family carers in providing continuity of care for care-recipients. HSCP acknowledgement of family carer expertise may be especially helpful given family carers in this study expressed feelings consistent with a lack of confidence and uncertainty in their ability to provide quality home-based care. In order to acknowledge the contribution of family carers in shared care partnerships, clinical interactions respectful of family carers views, judgements, opinions, and expertise are encouraged. SLTs seeking to understand patterns of care-recipient behaviour may significantly benefit from the opinion and perspective of family carers. Family carers may be able to make accessible the otherwise potentially inaccessible context of the care-recipient, which may be helpful in the construction of care-recipient QoL. An understanding of how care-recipients construct QoL is vital for SLTs attempting to provide person-centred care. SLTs have a depth of knowledge on the physiological risks of feeding and swallowing impairment, but families should be recognised for the intimate knowledge they have regarding the psycho-emotional and psycho-social impact of the illness on the lives of the members of the family unit. SLTs seeking to understand the depth and breadth of feeding, swallowing and mealtime changes in order to make appropriate, family-centred suggestions for management may significantly gain from this insight.

8.3.4 Limiting threats to family carer hope in the clinical interaction

In this study, hope was often a powerful facilitator of family carer coping (see section 4.2.5). Family carers provided evidence that threats to hope could arise during clinical exchanges, including those involving SLTs, and that ongoing internal work was required of family carers to maintain hope in coping with and adapting to the illness. While attention to the preservation of service user dignity, identity and QoL have been documented features of the perception of care quality in palliative contexts (Kelly et al., 2016), this study identified that quality of care could also be judged based on the impact of that care on family carers hope. Home-based care for PwMND could be negatively impacted if hope within the care dyad was threatened by HSCPs and family carers were reluctant to engage with or support the recommendations of HSCPs who did not attempt to maintain care dyad hope and optimism. When working in palliative care settings, SLTs who seek to

limit potential threats to hope may not only enhance the therapeutic relationship but potentially support family carer coping and adjustment, given hope is documented to impact coping and adjustment (Poppe, 2020).

8.4 Sensitively orientating the role of the speech and language therapist

SLTs are responsible for addressing the physiological, emotional and psychological implications of feeding and swallowing impairment, which encompass the lives of the care-recipient and impact the wider family unit. These needs may be met with different approaches which primarily foreground either the safety or the QoL of service users (Kelly et al., 2016). No standardised method of assessing swallow physiology in MND has yet been agreed upon (Epps et al., 2020), and the processes SLTs use to establish the extent of the psycho-emotional and psycho-social complications have not yet been described in the literature. Despite these gaps, SLTs have a duty to provide a complete and comprehensive assessment of swallow function (IASLT, 2022) so that informed decisions can be made regarding care. In order to be considered comprehensive, assessment should address all aspects of the biopsychosocial model, including the extent of the impact of feeding, swallowing and mealtime difficulties on the psycho-emotional and psycho-social status of care-recipients and family carers. Flexibility in the supports available to meet the needs of the family unit is required of SLTs. Foley et al. (2014b) outlined that opportunities to exert control in therapeutic exchanges influence the engagement of PwMND with healthcare services and that being able to engage with health services *on care-recipients' own terms* supports acceptance and coping with the illness. The findings of the present study suggest family carers of individuals with MND-related feeding and swallowing difficulties, much like care-recipients, benefit from opportunities to exert control and express choice. For family carers, decisions regarding the intensity of HSCP input, information sharing processes, the extent of the family carer role in supporting and implementing food, drink and mealtime recommendations, and family carer participation in training and skill development to support home-based care may provide opportunities for family carers to exert control.

8.4.1 Translating knowledge of the psycho-social consequences of feeding, swallowing and mealtime impairment into practice

SLTs working with both members of the care dyad in the management of feeding, swallowing and mealtime impairment require a comprehensive understanding of the impact of this disability on both the family carer and care-recipient. SLTs should be aware that illness-induced changes to eating, drinking and mealtime routines, together with changes recommended to manage difficulties in these areas (including diet and fluid

modifications, restrictions and compensatory strategies), may significantly impact routines and rituals important for inclusion, belonging, normalcy and identity (see section 5.2.4.1 and 5.4.3.4), as well as relationships (see section 5.4.3).

Care-recipient non-acceptance of the diet and fluid modifications suggested by SLTs was common in the reports of participants in this study, consistent with information on service user adherence to diet and fluid modifications in the wider context of oropharyngeal dysphagia (Krekeler et al., 2018; McCurtin et al., 2018). The present study provided evidence to suggest that family carers may align with care-recipients in their choice not to adhere to texture modifications, particularly if diet and fluid changes involve limitations to the intake of identity-linked food or drinks and if food and drink-related routines important in relationships could be adversely impacted. Knowledge of the impact of SLT recommendations on care-recipient dignity, identity, normalcy and relationships is required by SLTs so that care aimed at supporting care-recipients and family carers to negotiate these changes (also representing risks) can be appropriately situated within palliative care frameworks which promote service user control and choice.

Providing education to family carers on the impact of feeding, swallowing and mealtime difficulties on relationships and identity, as well as developing highly individualised recommendations and choices for managing difficulties, may help alleviate negative psycho-emotional outcomes associated with feeding and swallowing changes. An example of this drawn from the findings of the present study may be targeting family carer guilt by facilitating awareness that care-recipients may wish to continue preparing family meals even if unable to participate in mealtimes as this act may be identity-affirming. Maintaining eating and drinking routines within the care dyad or wider family unit by providing routine-specific recommendations to optimise QoL as well as safety (e.g., ensuring care-recipients are supported with opportunities to talk with their children at mealtimes by foregrounding their conversation during intake of food items that are most efficient to swallow) may also optimise outcomes within the family unit and maintain meal-based opportunities for care-recipient sense of purpose.

Caution regarding how SLTs approach family carers to support or influence care-recipient adherence to recommendations is required given the potential challenges this may present to the relationship between the members of the care dyad. Open discussion regarding options and choices following a comprehensive determination of risk may best guide decision-making. This approach is consistent with social models of healthcare (Clarke, 2010), whereby challenges to the relationship dynamics within the care dyad are limited. Ongoing monitoring for subsequent changes in status or perspective which could

influence collaborative goals set may help to ensure that goals set in therapeutic exchanges meet the current, evolving needs of the care dyad. SLTs who administer care that foregrounds the family relationship and reduces any threat to the relationship which could occur during SLT interventions may help to reduce negative psycho-social consequences for family carers, and improve family carers' ability to operationalise care to the best effect.

8.4.2 Providing care responsive to the coping and adaptation style of family carers

In this study, family carers described the experience of care as changeable with changes in their ability to cope with and adapt to ongoing feeding, swallowing and mealtime challenges. Family carers identified that their coping and adaptation abilities and styles impacted their success at facilitating care-recipient coping, and adaptation to the incessant losses associated with the illness. Family carer's coping and adaptation abilities impacted their capacity to be receptive to SLT interventions, to operationalise care through careful analysis and judgement of illness-related information, to problem solve, manage changes, make strategic decisions, and set goals as part of the care team. Identification of the coping and adaptation styles of family carers (e.g., Endler & Parker, 1990; Lazarus & Folkman, 1984) by SLTs who work closely with the members of the care dyad may help SLTs identify an approach to care that is accessible, and one which is aligned with the coping styles of the members of the care dyad. Awareness of family carer coping and adaptation styles may also better facilitate SLT identification of the most appropriate methods to address feeding, swallowing and mealtime difficulties within the care dyad.

8.4.2.1 Goal setting

Evidence in this study supports the collaborative nature of goal setting required in the context of MND care. Review and adjustment of goals set with members of the care dyad in therapeutic exchanges is required on an ongoing basis given the progressive nature of the illness and subsequent disability. Review and re-evaluation of the collaborative goals set is also required, given the potential for changing perspectives and preferences for care in the context of feeding, swallowing and mealtime difficulties. Consistent with Oliver (2016), the present study supports the assertion that continual reassessment of the needs of the members of the care dyad is required from healthcare services, given that acceptance and adaptation are ongoing and phasic processes. In the case of MND, this cycle of acceptance and adaptation (experienced as well as witnessed by the family carer)

is embedded within the context of a progressive illness, which has important implications for the responsiveness of healthcare services working with the dyad.

8.4.2.2 Sharing information with family carers

In this study, family carers reported that their needs changed over time and were highly dependent on individual circumstances, such as their level of acceptance, coping status and approach to coping. It is appropriate that SLTs check the information needs of the care dyad regularly, particularly at critical moments in the illness trajectory (e.g., the onset of feeding dependency), and offer information and support as indicated on the basis of need. Information made available in multiple formats, such as verbal, written and online information, as well as that designed to support all levels of health literacy (as well as meet the needs of non-English speakers), may enhance accessibility and support family carers to access information at times suitable to them. Family carers commonly experience feelings of overwhelm, and in this study, overwhelm was reported to impact family carers' ability to process and retain information. Given the high emotional demands family carers can be subjected to, and in light of the potentially sensitive nature of care-based information shared, being able to support flexibility in access to information may be most helpful for family carers.

Strategic communication was an essential dimension to how family carers provided care in this study. SLTs involved closely with the family unit in the delivery of care may be required to position themselves sensitively in order to participate in discussions around points of care which family carers do not feel comfortable initiating. Discussions regarding the role of gastrostomy feeding, eating and drinking with acknowledged risk and the requirement for nutritional surveillance were identified in this study as requiring particular care. Sterling et al. (2013) suggests that in some cases HSCPs may delay or avoid sharing information which implies observation of illness progression that they feel could negatively impact care-recipient psycho-emotional status, and that HSCPs may experience unease when confronting the care dyad with evidence highlighting poor prognosis. In this study, overt discussions around deterioration in care-recipient functional ability were met with resistance from some family carers given the negative impact on hope (see section 4.2.5). A balance is therefore required from SLTs with sharing information in a way which allows care dyads to have full access to the range of management options available, but that is sensitive to potential threats to hope and optimism when future care needs arise. Family carers in this study described being confronted by discussions regarding gastrostomy feeding if they considered discussions

to be initiated too early. Equally, family carers were angry and frustrated if discussions were not initiated in sufficient time to ensure all options for care were available.

Participants in this study valued the role of HSCPs in facilitating open dialogue within the care dyad, particularly when topics for discussion were sensitive or when decision-making preferences could be confronting. The role of formal care staff in protecting family carers from the responsibility to initiate sensitive care-based discussions was identified by family carers as especially important as family carers commonly believed the relationship with care-recipients could be compromised if they initiated these discussions. In many cases, family carers sought to avoid making their own preferences for the care-recipient's care known (especially decisions regarding end-of-life care) as they endeavoured to prioritise the traditional family relationship above the care-based relationship.

8.5 Indications for specific interventions within the scope of speech and language therapy practice

8.5.1 Choking management

Lisiecka and colleagues (2020) outlined that SLT support specifically targeting choking in the context of family carer distress is of paramount importance. Family carer distress associated with choking episodes is frequently reported (Neudert et al., 2001; Whitehead et al., 2012), and while the most recent international MND guideline (MND NZ, 2022) recommends that PwMND and their family members should be instructed on First Aid techniques, no detail is provided regarding how this should be organised within healthcare services. Specific recommendations to address choking are not yet provided in international guidelines on the management of MND (Andersen et. al., 2012; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020). Algorithms for choking management in the context of other progressive neurological illnesses (Parkinson's disease and related disorders) have recently been proposed (Ling et al., 2022). The utility of similar algorithms for family units impacted by MND has not yet been debated in the literature. While the management of medical emergencies in MND is discussed (e.g., Finsterer & Stöllberger, 2017), current levels of direction for families involved in pre-hospital care during potential terminal choking events are insufficient.

Monitoring for increased risk of choking in the event of deterioration to general medical status (including increased fatigue), reduced respiratory status, and/or progression of any additional difficulty with swallowing is required by to inform the risk of negative consequences of feeding and swallowing impairment, including choking (IASLT, 2021). In

the context of MND, objective data together with a careful clinical interview (including both members of the care dyad) may best enable the differentiation of choking on oral bolus versus penetration and/or aspiration of oral and pharyngeal secretions. This is important in MND as care dyads who have trouble differentiating between coughing and choking can overestimate choking instances (Hajikoutis et al., 2000), potentially exacerbating fear and influencing the management of oropharyngeal dysphagia.

Implementing care to reduce the physiological complications of feeding and swallowing impairment is part of the role of the SLT, and in the context of MND, careful attention to the heightened fear that care dyads experience relative to actual or potential choking is necessary. For SLTs, responding to this particularly distressing feature of the illness may alleviate unnecessary distress, avoid unnecessary limitations and restrictions in oral intake, alter perspective on disease progression and support the appropriate alignment of priorities for intervention. In light of the findings in this study which suggest family carers often have a preference for learning in the moment, SLTs who endeavour to ensure training is accessible to family carers on all aspects of the management of feeding, swallowing and mealtimes (including texture modifications, behavioural and compensatory strategies) and who provide ongoing education regarding indications for making contact with SLT services may enhance family carer confidence and potentially alleviate some of the fear associated with oral intake. In order for SLTs to be able to offer appropriate education and reassurance regarding choking as a (rare) cause of death in MND, SLTs should be knowledgeable about the evidence base documenting mortality associated with choking in the context of MND (e.g., Gil et al., 2008; Neudert et al., 2001; O'Brien et al., 1992). This information may provide reassurance and assist care dyads to make fully informed choices regarding oral intake if fearfulness of choking is significant, minimising the risk of potentially overly defensive care.

Participants in this study often described their intention to source training in First Aid, outlining the potential benefit of First Aid training for them in the context of choking (see section 5.2.1.2). First Aid training made available to family carers who wish to gain knowledge in the management of acute choking may be one way to positively impact family carer confidence and reduce fear. In this study, some family carers (i.e., those adopting a task-based approach to coping) identified several generic care-related skills in which they wished to receive further training, including communication skills and stress management. While the researcher acknowledges that First Aid training may not be appropriate for all family carers, for family carers specifically seeking First Aid training, increased opportunities to access this as part of a wider skills package (facilitated by

formal healthcare services), may be beneficial and could also strengthen the informal-formal caregiver interface.

8.5.2 Gastrostomy feeding

Decision-making regarding the potential need for enteral feeding in the context of swallowing disability is a typical component of advance care planning in MND (Andersen et al., 2012; Hardiman et al., 2002; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020). Failure to identify individuals who may benefit from this intervention early may preclude candidacy, given that the risks associated with the insertion procedure may increase with increased disease severity (NICE, 2019). Early gastrostomy tube placement is currently acknowledged as best practice in MND (NICE, 2019). While gastrostomy candidacy discussions are typically initiated by the medical team, SLTs involved with the management of swallowing difficulties may also identify a need for the initiation of these discussions based on observation of functional swallow decline.

Participants in this study understood the need for pre-emptive care in planning for gastrostomy and, despite experiencing difficulty with forced visualisation of future deterioration, acknowledged many challenges associated with this process were unavoidable. However, distress associated with gastrostomy planning for family carers was also reported to be exacerbated by factors family carers considered to be avoidable. Avoidable factors such as the timing of gastrostomy discussions were highlighted, whereby family carers expressed a preference for information regarding gastrostomy to be provided separately from the diagnosis given the traumatic nature of diagnosis and the degree of existential shock which resulted. Prediction of illness trajectory and the trajectory of swallow decline (e.g., rapid versus slow illness trajectory), as well as the sharing of information regarding care-recipient expected life span (often part of the discussions seeking gastrostomy feeding preferences), require great sensitivity. Evidence from this study highlighted potential opportunities for quality improvement in gastrostomy candidacy discussions when information regarding illness trajectory and expected decline in swallow functioning was provided insensitively or was inaccurate.

Additionally, some family carers suggested it might be useful for healthcare providers to seek family carer opinion on care-recipient readiness for advance care planning prior to approaching the PwMND (this aligned with the desire for family carers to protect the psycho-emotional status of care-recipients). Family carers felt their opinion on the care-recipient's psycho-emotional and coping status may inform decisions of healthcare professionals (HCPs) regarding the timing of gastrostomy candidacy discussions. Family

carers also expressed they would benefit from the opportunity to process information relevant to the indications for advance care planning prior to being in a position where they were required to support the care-recipient to emotionally navigate this decision-making process. This perspective is interesting considering a systematic review of decision-making between patients and family carers in MND found that family carers may experience higher levels of anxiety in making decisions about future care than PwMND do (Foley & Hynes, 2018), thus reinforcing the importance of considering the unique needs of each member of the care dyad.

As identified in this and other studies in MND, advance care planning may impact family carers' sense of hope and elicit a despair response as the gravity of the illness (i.e., the sense of life under imminent threat) becomes a reality (Lisiecka et al., 2020; Stavroulakis et al., 2016). Formal care providers, including SLTs, who seek to identify the information needs of family carers, explain potential misconceptions with reference to the current evidence base, and offer a mechanism for facilitating discussions on the potential role of gastrostomy within the care dyad, are encouraged to do so carefully and sensitively to enhance the outcomes of both family carers and care-recipients.

8.5.3 Eating and drinking 'at risk'

Family carers in this study described their distress when providing care to care-recipients who did not wish to adhere to the diet and fluid modifications recommended for the purpose of reducing the risk of negative physiological consequences of oropharyngeal dysphagia (see sections 4.2.2, 5.2.1.3, and 6.2.3). This distress was less problematic for family carers when care-recipients were at the end of their lives as a more distinct focus on enhancing care-recipient comfort was appropriate coinciding with the expectation of an imminent and unavoidable loss of life. In the earlier stages of the illness, family carers were often fearful of what they considered to be care-recipient risk-taking behaviours. These behaviours could result in an immediate and acute need for family carers to intervene to prevent loss of life (e.g., in the instance of a choking event) or which could result in an outcome potentially hastening death (e.g., the development of an aspiration pneumonia). As family carers assumed responsibility for care-recipient survival, careful balancing of needs and agendas in situations involving care-recipient non-adherence to feeding and swallowing recommendations was often required; this process could be both traumatic and destabilising for family carers.

Input into decisions regarding eating and drinking with acknowledged risk is a complex area of SLT clinical practice (O'Keeffe et al., 2023). Although the Royal College of Speech

and Language Therapists (RCSLT) have published guidance documents to inform decision-making processes in this area (RCSLT, 2021), guidance specific to SLTs practicing in Ireland is not yet available. Governing documents are required in Ireland, given the moral, ethical and legal considerations relevant to the Irish context. A protocol for eating and drinking with acknowledged risk specific to MND care, taking into account the complex challenges associated with this cohort, may reduce family carer burden. The complexities that arise when there are differences in intake preferences amongst the members of the care dyad, and when there is complete physical dependence on family carers for oral intake (with or without co-occurring cognitive involvement) require addressing in a systematic and comprehensive way.

While formal protocols governing clinical practice in this specific area are pending, SLTs should ensure they continue to offer a comprehensive evaluation of the impact of feeding and swallowing impairment across all domains of functioning. Every effort to gain a full understanding of *all* consequences involved with the available management options, to evaluate interventions which may reduce controllable risk, and offer ongoing training and support relative to recommendations made should be provided by SLTs (Soar et al., 2021). Currently SLTs are urged to gain a comprehensive understanding of the wishes of the care-recipient and to remain up-to-date, knowledgeable, and transparent regarding the evidence base on texture modified-diet and fluids, given erroneous SLT beliefs have the potential to impact decisions made by service users (McCurtin et al., 2024). SLTs contribute to capacity assessment, best interest and advance care discussions as part of a wider multidisciplinary team (MDT) (Soar et al., 2021), and this study described the negative impact of SLT intervention when comprehensive, holistic, family-centred care addressing these areas of practice did not occur.

8.6 Implications for service planning: Organisational level

8.6.1 The need for speech and language therapy services in palliative care contexts

Family-centred care is the ideal framework for care in MND, and given MND is a palliative illness, formal inclusion of the family and attention to the family-based consequences of MND in therapeutic interventions are recommended (Andersen et. al., 2012; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020). Administration of family-centred care in clinical practice where service needs are high and competing, may be variable. Despite formal acknowledgement of the requirement for services to extend and include important members of the family unit, funding for healthcare services in order to support this level of

care integration has not yet reflected the increased demand. The clinical complexity involved in managing the needs of individuals with palliative illnesses (such as MND) requires staff with specialist levels of skill and knowledge (Kelly et al., 2016). Services require adequate funding to achieve the flexibility required to respond to the needs of the care dyad, and prevent family carers from feeling abandoned. This sentiment was voiced by the family carers in this study and has been documented as part of the experience of family carers of people with oropharyngeal dysphagia induced by stroke (Robinson et al., 2022). As indicated by the findings in this study, family carers, care-recipients and SLTs require adequate clinical time to address the needs experienced by the family unit, which can rapidly change and intensify as the illness progresses.

8.6.2 Access to psychology and social work services for family carers in MND

Direct access to psychology and social work services (particularly within primary and community care settings) in order to provide a comprehensive package of care to the members of the care dyad may improve psycho-emotional and psycho-social outcomes for family carers. Within primary and community care services, psychologists are not yet recognised as core members of specialist palliative care teams. The National Clinical Programme for Palliative Care (NCPPC, 2019) has highlighted this as a gap. Social workers are acknowledged as a core member of the specialist palliative care team (NCPPC, 2019). However, access to social work services in community locations, particularly where specialist palliative care teams are not yet available, may be limited (All Ireland Institute of Hospice and Palliative Care [AIIHPC], 2022). This study demonstrated evidence of deep and complex psycho-emotional experiences shared by family carers in the context of feeding and swallowing disability and indicated the potential benefit of access to a heightened level of psychological and social support. Particularly for young families impacted by MND, the distress in mitigating the series of losses by family carers on behalf of the members of the family unit calls for a highly specialised approach. Given the high rates of anxiety and depression amongst family carers and the risk of a prolonged and complicated grieving process (Aoun, 2021; Aoun et al., 2020; O'Brien et al., 2016; Whitehead et al., 2012), access to formal psychological and social work supports, particularly for high-risk individuals, should be prioritised. While in the field of oncology there has been a recent recognition of the need for and a charge to improve psycho-social care for families impacted by cancer (Riba et al., 2023), similar has yet to occur in the context of progressive neurological illness.

8.6.3 The provision of case managers for the coordination of care

Findings from this study confirm the extremely heavy burden of care family carers of PwMND are exposed to on a chronic basis, of which feeding and swallowing disability are a part. While many factors contributing to the negative psycho-emotional status of family carers are unmodifiable, inadequacies in cohesion and communication amongst the formal healthcare team working closely with family carers in the community may be improved. Many studies investigating family carer needs in respect to the degree of burden they experience have identified a preference for the establishment of a formally designated case manager to facilitate the logistics of care; including enhanced information sharing (Bakker et al., 2015; Flemming et al., 2020; Hagena et al., 2014; O'Brien et al., 2011; Whitehead et al., 2012). In this study, family carers outlined frustration at the unnecessary burden on their time associated with the requirement to duplicate information for multiple members of the care team and to address incomplete or inaccurate HSCP relay of information, which was often difficult to communicate in the first instance. This finding reflects that of other studies in MND (Bolmsjö & Hermérn, 2001; Bolmsjö & Hermérn, 2003; Hughes et al., 2005; Mockford et al., 2006; O'Brien et al., 2011). The inconvenience family carers experienced which was associated with actions not being followed up on (as agreed) by formal healthcare staff (including those arising in the management of feeding and swallowing difficulties) negatively impacted family carers by contributing to frustration and loss of trust for the participants in this study.

Assignment of an appropriate case manager within the primary care team may be beneficial in providing a central point of contact for overwhelmed family carers who, given the large amount of information they receive (particularly in the early stages post-diagnosis), may not completely comprehend and retain information regarding the roles of all the members of the healthcare team. A case manager may have a role in negotiating mechanisms of communication with the team and could serve to limit the number of HSCPs involved in care at any one time, better streamlining care in the context of family overwhelm. Triaging the need for healthcare inputs through frequent monitoring of the physical, psycho-emotional and psycho-social needs of the members of the care dyad (as well as members of the wider family unit) and liaising with the relevant HSCPs to initiate supports (when required) could also reduce the demands on family carers. Facilitating reviews of the quality of home-based services and assisting the care dyad to interface with formal healthcare services, such as respite care services (i.e., acting as a formal healthcare liaison), may improve the integration of care services across care pathways and reduce family carer burden. Limiting the remit of the case manager to one individual

and focusing on the strength of that relationship as an ally in care may improve family carers' sense of being valued. The need family carers have to feel valued is consistently acknowledged (Galvin et al., 2018). Reducing family carer isolation and limiting the sense of abandonment reported by family carers when staffing inconsistencies and fluctuations occur within the wider care team may also be possible with formal case manager designation. An enhanced sense of privacy within the home, a reduced need to train multiple members of staff on the minutiae of care (demonstrated to be extremely important in the context of feeding and swallowing impairment), and an improved consistency of care (which is difficult to achieve when numerous services are involved) could be enhanced with the appointment of case managers.

8.6.4 Improved access to and availability of state-funded home help and respite services

Participants in this study identified that formal home and respite-based care services, funded by the Irish Health Service Executive (HSE) at least in part to reduce the burden of care for family carers, could vary in quality and were often insufficient to meet family carer needs. Formal care funded by the HSE to support informal care in the home (e.g., via mechanisms such as formal homecare packages) were limited in the number of care hours provided, and the structure of the hours provided was piecemeal. Family carers often lacked sufficient support to be able to take meaningful breaks from care duties (including those undertaken to optimise feeding and swallowing status) and participate in activities outside of the home which could be used to affirm their identity, allow for social connection, and enable family carers to divert their attention away from the illness temporarily. The scheduling of home help hours impacted the ability of some family carers to include care-recipients in mealtimes. Care-recipients with high needs for positioning and who were unable to access support from home help at the appropriate times could not be positioned safely for family meals. Similar difficulties in the availability of formal care required to support inclusion of family members during mealtimes have been reported by family carers of people with oropharyngeal dysphagia as a consequence of stroke (Robinson et al., 2022).

Paid care was reported by the participants in this study to lack reliability; this was particularly challenging for family carers as they were living in a state of existential uncertainty and unpredictability. Other carers who were supporting care in the home were often reported to require training on feeding and swallowing strategies to enable them to assist the PwMND. This placed demands on the time and energy resources of family carers who (particularly in the advanced stages of the illness), were largely resource

limited. In this way, even when formal care supports were available, family carers often felt it was easier not to use this resource to support feeding and swallowing-related care tasks.

Family carers reported that it was not always possible for long-established feeding and swallowing care routines that were maintained at home for the purpose of maximising care-recipient independence and QoL, to be continued when care-recipients accessed residential care services. Family carers often described institutional care as lacking in understanding regarding the importance of minutiae in swallowing care plans, which they considered to be essential to promote independent feeding and mealtime inclusion for care-recipients. Staff were at times perceived by family carers to lack awareness, understanding, and the resources required to maintain care-recipient feeding independence. Reports of care-recipient exclusion from meals and increased reliance on enteral feeding or reduced intake during temporary residential care were provided by family carers in this study. Frustration arose for family carers when residential care services were unable to deliver what they considered to be a satisfactory level of care, or care that was on par with that provided in the home by these heavily burdened family carers who had often received no formal training to do so. Guilt associated with being unable to provide home-based care in place of respite services in light of this context could contribute to family carer's reluctance to access these supports in the future, ultimately increasing their burden.

8.7 Conclusion

This study sought to access a deep understanding of the experience of family carers in providing care to PwMND who experience feeding, swallowing and mealtime difficulties, ultimately to support clinical practice in the field. This chapter has outlined multiple points to consider in clinical practice including specific logistical concerns in SLT care, the planning, framing and organisation of SLT services, and the integration of wider services who interface with family carers to enhance the delivery of healthcare for PwMND. While the most recent international clinical guidance documents broadly emphasise the integral nature of a whole family approach to management in MND (MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020), clinicians lack specific guidance to inform feeding and swallowing disability specific evidence-based care.

This study calls for attention from SLTs (as well as other HSCPs) involved in the clinical management of feeding, swallowing and mealtime disability induced by MND to appropriately acknowledge family carers as both informal care providers and as service

users. Examination of potential assumptions that underpin SLT expectations of family carers in therapeutic exchanges at all levels of care may be prioritised as a next step. With due consideration to the perspectives, position and expertise of family carers, SLT engagement and interaction with family carers, both as individuals supporting the PwMND to live with feeding, swallowing and mealtime disability at home and as individuals impacted by third-party dysphagia in MND may be enhanced.

As outlined throughout this chapter, significant gaps remain in the evidence base attempting to capture the impact of feeding, swallowing and mealtime difficulties in the context of MND. The next chapter (chapter nine) provides further detail on the gaps present in the evidence base and explains the value of prioritising these areas for future research.

Chapter Nine

Implications for future research

9.1 Introduction

The preceding chapter (chapter eight) presented implications for clinical practice arising from the findings of this study, specifically applicable to the practice of speech and language therapists (SLTs) working within feeding and swallowing disability in Motor Neurone Disease (MND). This chapter identifies avenues for further research, primarily focusing on continued interrogation of the psycho-emotional and psycho-social impact of feeding, swallowing and mealtime difficulties and the mechanisms best suited to identifying and addressing the needs of family carers through SLT-delivered care. Additional research aimed at verifying and consolidating the findings of this study, as well as further expanding into current gaps in the evidence base, is proposed. Progressing understanding of the experiences of feeding and swallowing disability for family carers using a multidimensional approach will serve to better inform healthcare service provision and policy.

9.2 Focusing the research to support evidence-based care

International guidelines, whilst predominantly focused on the management of the physiological aspects of the MND illness, have in recent years begun to acknowledge the extent of the impact of the psycho-emotional and psycho-social consequences of MND on the family unit (Andersen et. al., 2012; Miller et al., 2009b; MND NZ, 2022; NICE, 2019; Shoesmith et al., 2020). Recent publications have made specific references to the social consequences of feeding and swallowing difficulties in MND, calling attention to dysphagia-induced activity and participation limitations such as the withdrawal of care dyads from eating in public (NICE, 2019; Shoesmith et al., 2020). Although clinical guidelines promote family-focused intervention to address the extent of feeding and swallowing-related activity and participation restrictions, SLTs continue to lack specific guidance to inform standardised, consistent, evidence-based intervention (Epps et al., 2020). In order for clinical guidelines to include protocols for the comprehensive assessment and management of the psycho-emotional and psycho-social consequences of feeding and swallowing impairment, a more concentrated approach to research in this area is required. This chapter addresses the primary areas for further research arising from the findings of this study, focusing on: 1) data collection methods; 2) participant

demographics; 3) service design and delivery; 4) the perspective of the SLT; and 5) broader implications for research.

9.2.1 Indications for further family carer-based research concerning feeding, swallowing and mealtime experiences in MND

This section proposes multiple approaches to increase the depth of knowledge regarding the experience of family carers of people with MND (PwMND) who provide care to support care-recipients with feeding and swallowing difficulties. This includes using methods to compensate for the potential participant bias (e.g., recall, social desirability) associated with interviewing, as well as methods to investigate specific time-sensitive features of the family carer experience. Distinctive features of participant demographics within the wider family carer cohort are highlighted, given the potential for unique (demographic-based) differences to be uncovered. Features of SLT service design and delivery that may enhance the experience of family carers are also proposed for investigation.

9.2.1.1 Considering study design and procedures

It was not unusual for the participants in this study to describe being challenged when recalling specific details relative to the feeding, swallowing and mealtime-associated changes they experienced. Given similar challenges have previously been reported in studies using in-depth interviewing as the primary method of data collection (Lisiecka et al., 2020), exploration using alternative methods may be beneficial. An ethnographic study involving videorecorded footage of care dyads over mealtimes may elicit a detailed account of role and relationship changes within the care dyad, which is difficult to access through other methods. Extending this to evaluate the experience of mealtimes within the wider family unit would make a novel contribution and acknowledge the depth of the impact of mealtime changes. In-depth participant observation rather than in-depth interviews may also limit demand on participant time; this was acknowledged as prohibitive of family carer contribution in this study (see section 3.7.4). An ethnographic study collecting videorecorded data on mealtimes could be employed to further investigate relationship changes. Conducting, for example, a conversation analysis (Sacks, 1992) on videorecorded data could add another dimension to the current body of knowledge on the psycho-social impact of feeding, swallowing and mealtime changes within the family unit.

Numerous time and event-critical challenges in the experience of feeding, swallowing and mealtime changes, such as the onset of feeding dependence and the withdrawal of the care-recipient from family meals, were discussed by participants which appeared to significantly impact the caregiving experience. A targeted appraisal of timing and event-

critical factors via a longitudinal study (e.g., using mixed methods) is suggested to uncover a greater depth of information regarding possible events within the illness trajectory which exacerbate or contribute to negative family carer responses. Attrition is known to be high in longitudinal studies in MND. With the obvious exception of mortality, the reason for this is not fully understood (Atassi et al., 2013); this presents difficulty for researchers attempting to mitigate attrition in their studies. Attrition in longitudinal-based research can be challenging because of the need for the recruitment of a sufficient number of participants. Despite this, the importance of investigating the experience of family carers of PwMND in research that is longitudinal in nature has been emphasised (Conroy et al., 2023; Williams et al., 2008). If practically possible, a longitudinal study would be valuable to further inform how family carer needs evolve with the evolving illness. This information may also be useful to underpin the development of a tool which could enable SLTs to predict family carer tendencies towards more acute negative psycho-emotional and psycho-social outcomes as the feeding, swallowing and mealtime consequences of MND evolve.

The design, development and administration of a large-scale quantitative study to extend understanding of psycho-emotional and psycho-social challenges associated with feeding, swallowing and mealtime difficulties for family carers of PwMND is suggested. To date, data capturing the experience of family carers in this area has been derived from qualitative investigations only, and participant numbers have been relatively low. A larger-scale quantitative study (e.g., observational cohort study, cross-sectional survey) would make a useful extension to the current study and could be used to triangulate with this data set to inform service planning and policy. Access to specific information on relationship, role, and identity changes, as well as the psycho-emotional consequences associated with the presence of feeding, swallowing and mealtime changes, could be targeted.

The findings in this study demonstrate that, given that the psycho-emotional and psycho-social consequences of feeding and swallowing impairment in MND are complex and nuanced, it may be difficult to capture the experience of these difficulties for family carers in routine clinical exchanges. Standardised methods of evaluating and monitoring these aspects of feeding and swallowing disability for family carers would be beneficial. SLT input would be enhanced by the development of a family carer-reported outcome measurement tool that, following psychometric testing for reliability and validity, could be used to obtain information regarding the psycho-emotional and psycho-social consequences of feeding and swallowing impairment. At present, no validated tool is available to assess quality of life (QoL) for family carers of people with oropharyngeal

dysphagia (Perry et al., 2022). A tool that is repeatable is required given that the disease trajectory in MND is changeable, and family carer needs evolve in line with the intensification of care-recipient disability (Siciliano et al., 2017). A standardised method that can be used by SLTs to baseline psycho-emotional and psycho-social status, identify difficulty, monitor change, indicate meaningful family carer-specific goals, and evaluate the effectiveness of intervention is required. This tool should be developed as part of a core set of outcome measures establishing the impact of feeding and swallowing difficulties on family carers in order to enhance communication, not only amongst service users and clinicians but also amongst researchers working in this area. Such a tool could be developed to indicate the risk of exposure of family carers to negative psycho-emotional and psycho-social consequences of the feeding and swallowing disorder and help guide SLT intervention for PwMND and their carers. A family carer-reported outcome measurement tool may also allow greater accuracy in capturing the extent of third-party disability associated with feeding, swallowing and mealtime difficulties for family carers in the context of MND. When able to accurately identify the true cost of feeding and swallowing impairment, service planners may be better positioned to make informed recommendations regarding organisational structures required to optimise outcomes in this area. This avenue is therefore proposed as the highest priority for further research leading on from the current study.

9.2.1.2 Considering participant characteristics

The participants in this research varied greatly in relation to most demographic characteristics. However, all participants in this study were white, and almost all (20 participants) were white-Irish. The researcher acknowledges that the under-representation of individuals outside of a white-Irish population limits the extent of transferability of the study's findings. Further investigation of the family carer experience is indicated in more ethnically diverse and minority populations, both within and beyond Irish populations. Findings from healthcare research in other parts of the world indicate that race and ethnicity are factors that can influence service user perception regarding healthcare quality (Nelson, 2002; Welch et al., 2005). Distinct features of healthcare services considered essential to the perception of high-quality care for minority populations (e.g., demonstrating sensitivity to cultural factors such as language use and relationship norms), require uncovering in order to better serve under-represented family caregivers, increase inclusivity and illuminate preferences for care.

Although the overall numbers of young adult carers in this study were small, findings previously published regarding the increased susceptibility of young carers to negative

outcomes associated with caregiving, both in chronic illness (Keating & Eales, 2017) and in the context of MND (Foley et al., 2014a) have not been disputed by the findings in the current study. Five participants (Anthea, Hallie, Iris, Karen and Mike) were young adult carers of parents with MND (carer age range: 19 to 39 years). Changes in the traditional power balance within the relationship, and the extent to which traditional family roles were taken over by family carers when care-recipients (parents) were no longer physically able to fulfil these roles, appeared to be psychologically confronting in specific ways for young adult carers (see section 5.4.3.2). Unique challenges young adult carers may be exposed to, particularly in contexts where the financial, social and career-based consequences of caregiving are significant, appear to exacerbate the negative family carer experience (Schischlevskij et al., 2021). In the present study, unavoidable changes to the power dynamic within the care dyad (perceived by the family carer) impacted aspects of care such as care-based decision-making (including family carer perspectives on eating and drinking with acknowledged risk), and the ability of family carers to interface with health and social care professionals (HSCPs). Being able to highlight the specific needs of young adult carers who provide care to parents with MND-induced feeding and swallowing impairment and identify supports required to assist in care provision in this specific area may support care that is tailored to better meet the needs of the family unit. An investigation that specifically targets the experience of feeding, swallowing and mealtime changes for young adult carers in MND may help progress understanding of specific relationship and identity challenges, particularly those associated with the process "parentification" (Svanberg et al., 2011).

This study did not set out to exclude family carers of PwMND who were experiencing care-recipient cognitive impairment as part of the illness profile. However, no family carer in this study declared they were providing care to care-recipients with a formal diagnosis of cognitive impairment. A follow-up investigation of family carers of PwMND experiencing feeding, swallowing and mealtime difficulties with the additional presence of neuro-behavioural symptoms of cognitive impairment may extend the understanding of the impact of feeding, swallowing and mealtime changes on family carers. The presence of neuro-behavioural symptoms of cognitive impairment have been documented to increase the demand on family carers in their caregiving roles (Merrilees et al., 2010). In the context of feeding and swallowing difficulties, cognitive difficulties may exacerbate negative psycho-emotional sequelae for family carers (Clarke et al., 2018). Behaviour changes secondary to cognitive impairment may increase unpredictability for family carers, reinforce stigmatisation and magnify negative carer psycho-emotional sequelae (Keating & Eales, 2017; van Bruggen et al., 2016). The stigmatisation of individuals with

feeding and swallowing impairment and the factors that might be associated with this would benefit from further investigation. Awareness of the specific impact of care-recipient cognitive impairment (and subsequent behaviour change) on the feeding, swallowing and mealtime experiences of family carers could further inform family-centred care in MND.

9.2.1.3 Considering design and delivery of MND care services

This study contributes to the literature emphasising the psychological needs and risks for family carers of PwMND. As mentioned previously (see section 8.6.2), formal psychological services are not available (or yet recommended) as part of the core team managing the needs of PwMND and their family carers in primary and/or community services. Beyond the services in place at specialist MND multidisciplinary clinics, access to psychology services is often facilitated by voluntary bodies (e.g., the Irish Motor Neurone Disease Association (IMNDA)) or through private arrangement by families. Clinical guidelines in MND (Shoesmith et al., 2020) explain that a lack of evidence on the effectiveness of psychological interventions with families impacted by MND presents a barrier to formalising recommendations for the role of these professionals. While there have been a small number of studies published investigating psychological interventions for family carers of PwMND (de Wit et al., 2020; Harris et al., 2018; Marconi et al., 2016; Weeks et al., 2019), further research is a priority. There is momentum presently within the psychology and social work disciplines to gather the evidence required to illustrate benefits (Harris et al., 2018; Weeks et al., 2019). The ongoing need for additional psychological support is a frequent gap expressed by family carers (Schischlevskij et al., 2021). This was verified in the present study through numerous examples in the specific context of feeding and swallowing disorders, where family carer vulnerability to negative psycho-emotional and psycho-social consequences could arise.

Directing further investigative attention towards a range of psychological and social interventions may progress recommendations for improving the services available to care dyads. This may not only improve the experience of vulnerable family carers but may also assist HSCPs involved in managing the psycho-emotional and psycho-social consequences of specific MND-related disabilities (such as feeding and swallowing impairment) as a team. Potential scope for collaborations between SLT, psychology and social work services to optimise family carer outcomes could also be highlighted through additional research, addressing the global experience of distress from profession-specific perspectives in an integrated manner. Overall, the ways in which services are provided to family carers of PwMND in light of the distinct needs of family carers require interrogation.

The present study echoes previously documented sentiments that home-based care may not always be the best fit to meet the needs of family carers (Olesen et al., 2022). Given a heightened risk of adverse family carer responses to home-based care, domiciliary care in the context of SLT interventions for feeding and swallowing should be investigated regarding quality, suitability, and impact of care. Investigating SLT-administered domiciliary care may enable unmet needs and quality improvements to be identified, communicated, and implemented across the profession.

In this study, management of care-recipient behaviours typically aligned with the term ‘at risk feeding’, as well as management of care-recipient choking, were universally acknowledged by family carers to be a challenging part of caregiving (see sections 5.2.2, 5.2.1.2, 5.2.1.3, and 5.3). Particularly difficult situations arose for family carers when care-recipients were fully dependent for oral feeding, and when there was dissonance in perspectives regarding how to manage care-recipient swallowing disability in the context of “risk”. This challenge could be further complicated by the approach of SLTs, particularly when this approach had the potential to be overly cautious or defensive (McCurtin et al., 2024; O’Keeffe et al., 2021). Family carers who were challenged by care-recipient preferences to eat and drink ‘at risk’ were cognisant of the care-recipient’s need to exert control as autonomous individuals regarding their preferences for diet and fluids, as well as regarding the compensatory strategies they wished to engage with. However, the universal sense of obligation family carers felt to protect care-recipients from physical harm complicated eating, drinking and mealtime situations; this could be distressing as family carers attempted to balance, negotiate, compromise, and prioritise the competing needs. International SLT practice guidelines (e.g., RCSLT, 2021; Speech Pathology Australia [SPA], 2019) offer some direction to SLTs who facilitate complex decisions involving eating and drinking with acknowledged risk. The current lack of Irish guidelines (which are necessary due to differences in society, culture, and legislation internationally) means that the Royal College of Speech and Language Therapists document (RCSLT, 2021) may provide the framework SLTs use to inform care. The scope of the RCSLT (2021) document is broad, including practice considerations relevant to the wider population of individuals with dysphagia. Minimal attention is given to addressing the position of family carers who administer oral food and drinks to care-recipients when they are not physically able to self-feed. Key illness-specific challenges which arise in the context of MND, where complete physical dependence for feeding is common, require further clarification in formal guidance and/or consensus documents. In the present study ‘at risk feeding’ was generally less of a challenge for family carers in the advanced stages of the illness given that the focus of care was more distinctly aligned with the protection of

care-recipient QoL. Further research specifically aimed at identifying the key concerns of care-recipients, family carers, and SLTs either experiencing or involved in providing care in this context may help inform Irish policy documents that are clear, comprehensive and adequately attend to the position of all individuals involved.

Associated with 'at risk feeding', there is a limited amount of published data on choking-related mortality in MND (Gil et al., 2008; Neudert et al., 2001; O'Brien et al., 1992). Given the evolution of the clinical management of MND and the need to account for variation in practice internationally, a contemporary investigation on mortality associated with choking for PwMND would be useful. Updated information regarding mortality associated with choking in MND is required to support the education of family carers who make contributions to decisions regarding eating and drinking for care-recipients. This information could be useful to ensure that family carers' perception of risk is justified in the evidence base. As noted by Galvin and colleagues (2018), family carers need the appropriate knowledge, skills and judgement to be able to adequately provide care. It is important that HSCPs support family carers as well as possible to do so.

9.2.2 Indications for speech and language therapist-centred research

HSCPs, including SLTs, are encouraged to provide care that is responsive to the needs of family carers of PwMND. With the exception of brief recommendations for HSCP care delivery within the context of specialised MND multidisciplinary clinics (Andersen et. al., 2012; NICE, 2019; Shoesmith et al., 2020), guidelines to direct how SLTs work with families affected by MND in primary, community, and home-based care settings are not yet available. SLTs in Ireland do not yet have guidelines informing management in the broader context of palliative care (across aetiologies), despite this being recognised as an area of work demanding high levels of skill and expertise (Kelly et al., 2016). Understanding the current methods used to organise and deliver SLT care in the context of MND, including the healthcare models SLTs use to frame service provision (e.g., foregrounding the medical versus the social model of healthcare), may uncover challenges to the provision of sensitive, flexible and responsive care. Care of this nature is not only vital in supporting the empowerment of service users but also necessary given it is considered best practice (Hardiman et al., 2002).

SLTs working within primary and community care settings are typically responsible for delivering care to a wide variety of individuals (at times both adult and paediatric service users) with communication and swallowing difficulties arising from a vast array of aetiologies. In the Irish context, seamless systems of integrating primary and community

care services with specialist MND multidisciplinary teams (MDT) and specialist palliative care services have yet to be achieved (AIIHPC, 2022; Ward et al., 2022). The variability in integration of primary, secondary and tertiary healthcare services is consistent with that observed in interdisciplinary teams working within primary care teams in Ireland (Tierney et al., 2019). The Irish Health Service Executive (HSE) National Service Plan (2023) and the Sláintecare Implementation and Action Strategy (Government of Ireland, 2021) reinforce the importance of re-orientating healthcare service delivery from acute care towards community-based care to enhance service user and family-centred outcomes. However, given that MND is a rare condition (Ward et al., 2022), HSCPs in primary care settings typically do not have a wealth of experience working with families impacted by this illness. With respect to the role of general practitioners (GPs), delays in diagnosis have been documented due to the lack of familiarity with this illness, this can reduce the timeliness of life-prolonging interventions and contribute to reduced service user confidence and trust (Hardiman et al., 2002). In relation to SLT management, suboptimal management of communication and swallowing disability given a lack of experience with this illness risks heightening levels of disability across all domains of functioning. A worsened experience of the pre-terminal and terminal stages of the illness, not only for the person directly impacted by the illness but for members of the wider family unit, could also occur.

The development of practice-governing documents which promote social models of care (Clarke, 2010), and emphasise the combined social, cultural, political, and economic context of health, is essential to guide evidence-based interventions and reduce vulnerability to poor outcomes for individuals accessing SLT services. Understanding the current level of education, training and care provided by Irish SLTs in the management of feeding and swallowing impairment in MND is required in order to baseline current practice. By investigating the training received by SLTs to support dysphagia management, including the methods used to assess and characterise feeding and swallowing disability, set goals, intervene and measure outcomes across all domains of feeding and swallowing disability in MND, inconsistencies in practice as well as priorities for making impactful changes to SLT practice may be highlighted.

The most recently published review of trends in the literature describing dysphagia in MND illustrates the ongoing dominance of physiological impairment and physiological sequelae (including penetration, aspiration, and oropharyngeal residue), as well as symptom management primarily aiming to prolong life (Waito et al., 2017). Enteral feeding combined with behavioural and compensatory strategies used to overcome physiological

impairment are frequently reported (Waito et al., 2017). There is an absence of management strategies used to address the psycho-social and psycho-emotional consequences of oropharyngeal dysphagia in the current evidence base. Additionally, the newest developments in oropharyngeal dysphagia in MND have focused on swallow physiology (e.g., examining the potential role of early swallow rehabilitation in the maintenance of physiological function (e.g., Rogus-Pulia & Plowman, 2020)) rather than focussing on the full extent of the disability as it impacts activity and participation. While there has been limited attention to QoL and the relationship between swallow impairment and QoL for family carers of PwMND, studies are emerging in this area which attempt to document the extent of third-party disability in oropharyngeal dysphagia (Lisiecka et al., 2020). In light of recent emphasis that mainstays of management of physiological swallow impairment, such as diet and fluid modifications (Robbins et al., 2002), are not only difficult to tolerate (Krekeler et al., 2018; McCurtin et al., 2018) but potentially harmful for people with oropharyngeal dysphagia (O'Keeffe et al., 2023), attention to the development of this evidence base is essential.

Investigating the experience of Irish SLTs working with families impacted by MND may have important implications for the establishment of support for SLTs. Providing formal healthcare services to families impacted by MND is understood to be distressing (Olesen et al., 2022; Sanchez-Reilly et al., 2013). Contributing factors to this distress include a lack of time, knowledge, and confidence; being faced with moral dilemmas, ethical challenges, and conflict; and working closely with family units impacted by sorrow (Olesen et al., 2022). Research directed at SLTs providing care in the context of MND could better identify the capacity for and experience of providing family-centred care. The processes and strategies used in the building and maintenance of therapeutic relationships, the models of care predominant in service delivery and key barriers and facilitators for SLT practice could be emphasised in future research. Indeed, interrogating the predominant ideologies which underpin the practice of SLTs working with families impacted by MND as well as those within the wider palliative care context could provide an important perspective as to how SLTs themselves cope and adjust in professionally confronting situations. Further interrogation of the predominant ideologies which underpin practice could also offer an understanding of how professional actions may be influenced by unconscious personal bias. Such data could point to certain tendencies of SLTs who interact with families impacted by MND (e.g., providing insight into how clinicians construct and apply definitions of hope, hopelessness, and false hope in clinical interaction) and could help to facilitate family units coping with the effects of MND.

9.2.3 Considering broader research implications

This chapter has suggested a number of avenues for further research in this substantive area which were highlighted by specific findings in this study. In a more broad sense, this study also has important society-based implications for research. The participants in this study described feelings of sadness, embarrassment and shame when witnessing their family member contend with feeding and swallowing difficulties while in public. Family carers in these situations were cognisant of care-recipient's vulnerability to adverse social judgement when feeding and swallowing difficulties were visible to others. The visibility of feeding and swallowing disability was identified by family carers as negatively impacting on care-recipient's sense of identity. However, family carer's perception of negative social judgement in the context of feeding and swallowing disability in this study led to family carers supporting care-recipient withdrawal from social eating situations which were important for the protection and maintenance of family carer's own identity. Public awareness of feeding and swallowing disability is limited (McHutchion et al., 2021) and there is limited evidence describing how people with feeding and swallowing disability are stigmatised (Padilla et al., 2019). Focusing research attention in this area to illuminate the view of society on feeding and swallowing disability and to understand how society's views impact the treatment of individuals with feeding and swallowing disability within the community is required.

Building the evidence base with respect to the view in society of feeding and swallowing disability could start within smaller social contexts such as residential, respite and hospice-based care. Family carers in the present study expressed frustration when care-recipients were not supported to maintain mealtime routines within formal residential healthcare settings given the significance these routines had on the care-recipient's sense of dignity, identity, psychological and nutritional status. Given the lengths that family carers often went to in supporting mealtime preferences for care-recipients, this frustration was not unexpected. Multiple participants in this study highlighted feelings of guilt and frustration when interfacing with formal healthcare services as it was felt by participants that care-recipients were unable to access the level of support they required to participate in mealtimes. Careful attention to the minutiae required to support PwMND with eating and drinking routines (commencing with the initial mechanisms for communicating care-recipient care needs) was acknowledged by participants to demand significant resources from formal care staff. An investigation of mealtime experiences within respite and residential care settings for PwMND, and of the perception of feeding and swallowing disability for staff within these settings, may identify processes involved in mealtime

management and highlight potential areas for improvement that could better accommodate the preferences of both PwMND and family carers. In order to respond to the real-life concerns of family carers of PwMND who experience feeding, swallowing and mealtime difficulties, attention to supporting family carers in residential settings as they interact with formal care providers may inform and enable the prioritisation of impactful avenues for positive change.

9.3 Conclusion

This chapter has highlighted potential areas for future research that, if conducted, would enable comparison with (and possible extension to) the findings of the present study in order to build the evidence base on third-party disability in feeding and swallowing impairment in MND. The value of considering additional research designs, such as qualitative research utilising alternative methods of data collection (e.g., collecting videorecorded data in an ethnographic study), as well as quantitative approaches (e.g., including longitudinal studies and cross-sectional surveys), has been outlined. Suggestions regarding participant-specific characteristics in need of interrogation (e.g., targeting young adult family carers and those providing care to family members whose feeding, swallowing and mealtime challenges are complicated by the presence of cognitive impairment) have also been made, given the tendencies in family carer action and interaction are identified in this study as potentially associated with these characteristics.

An evaluation of the perspective of SLTs who work with care dyads in the context of MND has been identified as necessary to inform knowledge regarding barriers and enablers that may influence the success of care delivered to families impacted by feeding and swallowing disability in MND. Attention to the experience of formal care providers who deliver care in residential settings (i.e., respite care services) was also implicated through an appraisal of the findings of this study and in consideration of the current body of research on third-party disability in feeding and swallowing impairment in MND. Despite numerous opportunities to further contribute to the evidence base, the researcher suggests that the most immediate priority leading on from this study is the construction and psychometric testing of a tool to baseline and monitor the psycho-social and psycho-emotional outcomes of family carers of PwMND as they relate to feeding, swallowing and mealtime disability. The next chapter (chapter ten) concludes this thesis with an outline of the strengths, limitations, and key contributions of the study.

SECTION FIVE

CONCLUSION

Chapter Ten

Conclusion

10.1 Introduction

This study makes a significant contribution to the evidence base through the development of a conceptual framework documenting third-party disability in Motor Neurone Disease (MND) from the specific perspective of feeding, swallowing and mealtime difficulties experienced by family carers. Uncovering key processes central to the experience of family carers was integral to this investigation, given the dearth of evidence currently available in this area. Through in-depth investigation of the perspectives of family carers, knowledge regarding how family carers engage with care-recipients, members of the wider family unit, and healthcare professionals (HCPs) throughout the trajectory of care has been generated. The findings of this study make a unique contribution to understanding how caring in the context of MND can be impacted by feeding, swallowing and mealtime difficulties. The information derived from this study is necessary to ensure that health services can be planned and delivered in a manner which is responsive to family carer needs. This chapter documents the strengths, contributions, challenges and limitations of this study, and summarises the contribution made to knowledge before concluding this thesis.

10.2 Strengths and contributions

To date, there has been a scarcity of research attention, with only one study (Lisiecka et al., 2020) attempting to address the concerns of family carers over the full range of MND-related feeding, swallowing and mealtime difficulties. The Lisiecka et al. (2020) study included a small cohort of participants (n=10), with the perspectives of family carers sought as part of a larger phenomenological study primarily focused on the experience of the person with MND (PwMND). While Lisiecka et al. (2020) presented useful insights into family carer experience which have been verified in the current study, the study was insufficient to offer an explanatory account of the family carer experience afforded through the grounded theory (GT) approach used in the study which has been reported in this thesis. The development of an explanatory account of family carer experience is necessary to inform the design and delivery of healthcare services sensitive to the needs of family carer and this is a strength of the present study.

GT methodology (Corbin & Strauss, 2008/2015) has not yet been used to investigate third-party disability in the context of feeding, swallowing and mealtime impairment in-depth. This study has provided new insight into the value and applicability of GT as an approach in this field. Using GT methodology (Corbin & Strauss, 2008/2015) enabled the identification of a core category (*protecting*) in this study, key to explaining the processes underpinning family carer behaviour in feeding, swallowing and mealtime-related events and situations. Being able to situate the core category (as well as sub-ordinate categories related to this core category) within a conceptual framework which addresses the contextual and conditional factors influencing family carer experience is useful for structuring understanding regarding this topic of concern. The end-product in this research project, the explanatory conceptual framework was made possible through the choice to use the GT method (Corbin & Strauss, 2008/2015).

In this study, research attention focused solely on the perspective of family carers, as fundamental to the study was the acknowledgement of the broad impact of the illness on the family unit, and the value of family carers as vital partners in care. The current study highlights the contribution family carers make in undertaking their role as caregivers, not only for the recipients of their care, but also for members of the wider family unit. The primacy of the role of family carers in supporting the work of the numerous formal care providers involved in MND-related care has been foregrounded. Multiple obstacles and enablers to care which may arise during the informal care – formal care interface in the management of feeding, swallowing and mealtime challenges have been described in the findings of this study. This information facilitates a better understanding of the dimensions of the family carer – health and social care professional (HSCP) relationship which are particularly valuable to family carers, but also informs HSCPs on how they can operate effectively with family carers to support these preferences. Healthcare that is not only task-focused but relationship orientated is promoted via the findings of this study, consistent with palliative care ideals.

Although this study focused on the experiences of family carers, parameters of the experiences of PwMND from the perspective of family carers, which have not previously been described, have been illuminated. Numerous features of the experience of feeding, swallowing and mealtime difficulties appear to be shared amongst the members of the care dyad, but many aspects are distinctive to the experience of family carers. This study has provided a conceptual framework which can be used in the future to compare the experiences of the family carers who participated in this study with other cohorts of family carers as well as with the experiences of PwMND, speech and language therapists (SLTs)

working with families impacted by MND, and family carers of individuals with other progressive neurological illnesses.

In this study, the researcher adhered to the core processes required of GT methodology (Corbin & Strauss, 2008/2015; Timonen et al., 2018) to enhance the rigour and robustness of this research (see section 3.12). Detailed accounts explaining how the study was enacted (i.e., the audit trail) have been provided to ensure that this research may be repeated in the future. Extending this research to other groups of family carers to reduce the risk of potential erroneous extrapolation of findings in clinical practice has been supported with the foundation provided in this thesis, which includes an in-depth description of the research processes used.

10.3 Challenges and limitations

Participant recruitment was the most significant challenge in this study, and a prolonged recruitment period was required to respond to this challenge. Challenges in recruitment were pre-empted through the pilot study which preceded the current study (Daly & Jagoe, 2016), and attempts were made to minimise the impact of anticipated difficulties based on information from this pilot. The researcher used multiple avenues of recruitment, multiple gatekeepers and arranged access to potential participants via a number of recruitment sites to facilitate recruitment. Despite these strategies, the response rate proved lower than expected. Similar challenges have been reported in other studies investigating the experience of family carers and are particularly apparent in MND-specific studies (Herz et al., 2006; O'Brien et al., 2012). In this study, the researcher's base was located off-site from the primary recruitment location at the National Centre of ALS/MND at Beaumont Hospital, Dublin. Given this arrangement, it was difficult to foster a consistent sense of gatekeeper activity throughout the recruitment process. The researcher in this study did not, at the outset of this study, seek specific data regarding the number of potential participants approached by the gatekeepers, or the reason potential participants who were approached by the gatekeepers declined involvement. Future studies would benefit from capturing this information to inform processes which could enhance recruitment and identify any potential systemic difficulties (e.g., paternalism) impacting recruitment. Ensuring researcher access to the specialist multidisciplinary clinic to act as an advisor to gatekeepers as well as to enable collection of data onsite during routine clinic visits may optimise future participant engagement with studies of this nature.

The nature of progressive neurological illnesses means that the profile of illness and illness-related disability deteriorates over time. In the case of MND, illness progression

can be rapid or prolonged and is often variable (Harwood et al., 2012). This can impact the success of recruitment as family carers may be less willing to invest time and energy into research when embracing new illness-related change. This study was not designed to evaluate temporal conditions impacting family carers in a comprehensive or systematic manner. The data collection method in this study included interviewing each participant once only. Temporally linked contextual conditions important to the experience of family carers did arise in this study and, as previously discussed (see section 9.2.1.1), require further attention through prospective longitudinal research.

This study under-utilised public and patient involvement (PPI), now a mainstay of healthcare research in Ireland (Health Research Board, 2021). While the pilot study (Daly & Jagoe, 2016) sought feedback from participants regarding the recruitment strategies and interview schedule used, further partnership with a PPI advisory group may have afforded the opportunity for recruitment challenges to be addressed using strategies not within the researcher's consciousness. It is also possible that participant confidence and trust in this project could have been enhanced through formal collaboration with a PPI group. The newly formed Irish MND patient advisory panel may prove an invaluable resource for future researchers, supporting due cognisance of all factors necessary to consider throughout the research process.

10.4 Consideration of study procedures

The aims and objectives of this study called for an in-depth investigation of the experience of feeding, swallowing and mealtime difficulties for family carers and, as such, required a qualitative approach. While qualitative approaches enable the uncovering of contextual and causal factors relevant to participant experience, a potential disadvantage in respect of the ability to achieve "pure" objectivity is apparent. In studies involving human interpretation, there is always subjectivity. There may be unavoidable "biases" (subjectivities) that can be obvious or made obvious, and biases which are not obvious but remain fundamental in shaping world views. The purpose of interpretative research approaches, such as the approach used in this study (Corbin & Strauss, 2008/2015), is not to uncover undisputable truths; the researcher is interested in how experiences may change with changeable causal and contextual conditions. Access to truth with respect to social phenomena is considered by the researcher to be only possible by investigating a range of individuals with different perspectives which shape their formation and representation of this truth (Pawson & Tilley, 1997).

The inclusion and exclusion criteria in this study were broad and subsequently the demographics of the participants were largely heterogeneous. The researcher did not include purposeful stratification. Restrictions were not imposed regarding participant status as a *primary* caregiver to acknowledge those family carers who provide care within family care teams. Of the 21 participants recruited for this study, most (n=17) identified themselves as primary caregivers; Anthea, Mike, Iris, and Una were exceptions. Family carers in this study were not required to reside with care-recipients but most were or had been prior to bereavement (n=17); Hallie, Iris, Mike, and Una were exceptions. Eighteen of the participants reported they spent the majority of mealtimes with care-recipients; Hallie, Mike, and Iris were exceptions. Although broad inclusion criteria may be problematic when considering the strength of trends identified (Ritchie, 2003), the researcher felt the broad inclusion criteria in this study was an advantage given the dearth of research in the area and the benefit of generating a conceptual framework from the perspective of a heterogenous sample of family carers. Broad inclusion criteria allowed for the observation of an extensive range of factors potentially associated with the experiences of family carers in the context of feeding, swallowing and mealtime difficulties. Given that this study is the first to attempt to move beyond description to provide an explanatory account of the processes underpinning family caregiver experience in the context of MND-related feeding, swallowing, and mealtime difficulties, identifying participant characteristics which warrant attention in future studies was the researcher's intention.

Diversity within the demographic characteristics of participants in this study was apparent, although homogeneity in participant demographics was also noted. No family carer in this study was providing care for a care-recipient who was unable to eat or drink even small amounts; every family carer was involved in the preparation and facilitation of oral intake of some level. The inclusion of carers of PwMND who were unable to eat and drink orally may have been desirable to offer another dimension to the perspective of family carers. The female 'voice' in this study (n=13) was more strongly represented than the male (n=8) and this is consistent with the demographics of other studies on family caring in MND (Galvin et al., 2018; Lisiecka et al., 2020). Almost all participants (n=20) were of white Irish decent. The researcher acknowledges that the study sample reflects a narrow cultural base. The findings in this study relate only to the cohort of participants under investigation and cannot be considered universally applicable to the global population of family carers of PwMND who experience feeding, swallowing or mealtime difficulties. Further studies including a greater level of diversity pertaining to participant demographics are required to enhance transferability. Many dimensions in this study which were relevant in shaping the

experiences of family caregivers (e.g., individual, family and society-level conceptualisation of illness and disability, and levels of family unit cohesion and flexibility) may be influenced by cultural and/or gender-based contexts. The conceptual framework which represents the findings in this study is not intended to be generalised to other populations without verification.

Data collection for the first 17 interviews in this study took place face-to-face. However, data collection continued into the Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) pandemic-related social restrictions period, with the last four interviews conducted remotely. Multiple psycho-social consequences of the SARS-CoV-2 pandemic have been documented (Devaraj & Patel, 2021). The researcher acknowledges the potential for the unprecedented social context of the pandemic to significantly influence the experience of family carers. Not only were social food and drink routines and rituals of interest altered because of social restrictions, but exacerbated levels of negative psycho-emotional sequelae (including depression and isolation) were also noted amongst family caregivers during this period (Gallagher & Wetherell, 2020). Of the four participants in this study who were recruited during pandemic-related social restrictions, three participants (Steve, Tony, and Una) were bereaved carers whose experience of caregiving predated the pandemic. The overall impact of pandemic-related social restrictions on family carer's experience of feeding, swallowing and mealtime difficulties, as captured in this study, is therefore considered by the researcher to be low.

Remote methods of interviewing may limit the ability of the interviewer to identify and respond to nuances in non-verbal communication, which may be easier to identify in person (Foley, 2021). The establishment of rapport may be a challenge for researchers using remote methods of data collection and this could impact trust, the sharing of information and ultimately the credibility of findings. Prior to collecting data remotely, the researcher had been made aware of the potential limitations associated with remote interviewing, having pivoted to remote methods of practice for clinical SLT work. Her intra-interview conduct purposefully mitigated limitations in access to non-verbal communication by discussing limitations overtly with participants and using strategies such as directly checking the status of participants as well as verifying participant preferences regarding the ongoing interview with a higher frequency compared with that which took place in face-to-face interviews.

Many participants in this study sought information regarding the researcher's own background and experience during data collection, which the researcher. This sharing of the researcher's clinical background is acknowledged as a potential biasing factor in

participant responses in this study. However, to refuse to share information with participants when directly requested to is likely to have significantly impacted the extent to which participants shared their own experiences. When requested, the researcher declared her position as a practicing SLT currently working within the context of chronic and life-limiting illness (as stated in section 3.5). This experience includes working with PwMND as well as family caregivers in acute, primary and community care, and domiciliary settings. Although the researcher's background undoubtedly influenced her lines of questioning, the influence of the researcher's background and experience is proposed as a strength rather than a limitation in this instance. Through clinical experience, the researcher was sensitive to a range of concerns which could arise for family carers. Having practiced within the public healthcare system in Ireland clinically for 20 years, the researcher was able to avoid spending data collection time orientating to well-known features of the healthcare system in Ireland, within which family caregiving in this study was situated.

The strategies the researcher employed to manage the impact of researcher subjectivity were largely dependent on her insight into her positionality. Potential unconscious prejudices, by nature not specifically controlled for, may have influenced the interpretation and presentation of the findings for this study. The range of strategies used to enhance the robustness of this study, called for within the methodological requirements of GT studies and enacted within the confines of what was practical given academic institution-governed time constraints, sought to address researcher subjectivity. Information obtained in participant interviews, which were the main source of data in this study, may be influenced by the participant's ability to recall events successfully and authentically, as well as their desire to present a socially acceptable self (Weiss & Fine, 2000). During data collection, the researcher observed that some participants were visibly uncomfortable describing their own negative thoughts and aversions to the feeding, swallowing and mealtime difficulties they had witnessed. Potential conflicts between participant's own experiences and traditional beliefs regarding *who* and *what* a good carer does, may be one explanation for this discomfort. Evidence in this study found that family carers attempted to reduce their own potentially stigmatising actions towards care-recipients as they engaged in protection of care-recipient psycho-emotional status, dignity and quality of life (QoL) (see section 7.2.3.1). In the case of the two interviews where the PwMND wished to remain present with the family carer (John and Peter), the presence of these care-recipients certainly impacted the lines of questioning pursued by the researcher, including questions investigating potential stigmatisation. The presence of the PwMND is noted almost certainly to have impacted the responses of these two participants across a

number of areas, given this study emphasised role, relationship and identity challenges and changes in the context of the care dyad. With the presence of the care recipient, the participant's opportunity to speak freely was limited.

This study involved a number of bereaved family carers (n= 5) and as such biases associated with participant bereavement status require consideration. Bereaved participants are potentially vulnerable to attentional bias for mood-congruent information, as mood and emotional processes, both at the time of events and at the time of recall, are known to have the potential to influence recall for bereaved participants (Addington-Hall & McPherson, 2001). The researcher was interested in capturing family carer experiences across the entire continuum of care, and as such, the inclusion of bereaved family carers in this study was necessary. There are many potential sources of bias when conducting studies on human experience, from initial biases associated with the type of individual willing and motivated to participate in research studies to the natural tendencies regarding how individuals present themselves in research interviews. Participant biases, in many cases, are beyond the control of researchers. Despite this, they are acknowledged by the researcher as requiring consideration in the interpretation of the findings of this study.

The researcher's level of engagement with literature within this substantive area prior to data collection was aligned with that acceptable given the specific approach to GT taken (Corbin & Strauss, 2008/2015). The motivation to complete this study arose because of a clinical scenario the researcher was involved with. Through clinical practice, significant gaps in the evidence base required to direct intervention became apparent. There is debate among grounded theorists regarding familiarity with the extant literature at the outset of data collection (Timonen et al., 2018). Classic grounded theorists advise against researchers being familiar with or familiarising themselves with the literature (Glaser & Holton, 2004). Constructivist grounded theorists take a more pragmatic approach cognisant of academic institution processes which typically require at least some level of engagement with the literature (Charmaz, 2014). This researcher's position is aligned with that of Timonen and colleagues (2018), who assert that as long as the researcher ensures they remain open to the data, does not force data according to preconceptions, and appropriately appreciates unanticipated findings, then familiarisation with the literature is acceptable.

The researcher attempted to analyse the data immediately following each interview with the participants. However, complete analysis of the data prior to additional data collection was not always possible. Factors such as accommodation of participant availability and participant preference for data collection impacted the researcher's ability to complete

analysis in full after each interview. The analysis process in GT studies is understood to be time-consuming. While formal analysis is preferred prior to further sampling, particularly in the case of theoretical sampling, it is recognised that full analysis of data is not always practical (Timonen et al., 2018).

Member checking is commonly conducted in qualitative research to enhance the credibility of findings (Birt et al., 2016). However, member checking is not considered necessary within the approach to research taken in this study. Analysis during the advanced stages of coding in Corbin and Strauss (2008/2015) GT involves high levels of abstraction with attention to trends and tendencies dependent on context, rather than attempting to capture (exactly) the experience of each individual. In this study, participants were provided with the opportunity to review their interview transcripts and were invited to make changes to these transcripts. Consultation with the participants regarding the end-product for this study, the conceptual framework, did not occur, and neither was it considered necessary, on the basis of the level of abstraction required to achieve this end-product.

This study did not seek to establish the impact of MND-induced communication difficulties on family carers of PwMND, given that the researcher was interested in eating, drinking and mealtime-related changes only. However, this study did illuminate psycho-social processes and changes (including identity, role, and relationship changes), which, given that the experience of feeding, swallowing and mealtime difficulty was contextualised within wider illness-related changes, are also likely apparent in family carer's experiences of communication impairment. The family carer experience of communication disability associated with MND is an area which requires further investigation. The clinical implications of the current study, particularly those guiding SLT service delivery and design, have been made solely from the perspective of the findings of this study, which emphasise feeding, swallowing and mealtime difficulties. Qualitative investigation regarding the experience of communication difficulties for family carers of PwMND is required to inform SLT clinical services to reflect the extent of the role of these professionals more accurately. Unearthing further information on the full range of disabilities SLTs seek to assess, diagnose and manage is necessary to enable comprehensive care for families impacted by MND.

10.5 Summary of contribution to knowledge

The conceptual framework produced as the end-product of this research is the first representation of an explanatory conceptual framework depicting the key concepts relevant in understanding how family carers experience feeding, swallowing and mealtime

challenges associated with MND. This conceptual framework has provided a detailed account of contextual and causal conditions which influence the experience of family carers and subsequently result in behavioural tendencies in the context of feeding, swallowing and mealtime-related events and situations, including those which may occur in clinical situations. This study has achieved the objectives of identifying challenges experienced by family carers in mealtime situations and explaining relationship changes which can occur within the informal care dyad in the context of MND-induced feeding and swallowing disability. Thus, this study has contributed to current knowledge regarding the depth, breadth and complexities of the role of the family carer in the context of MND-induced feeding and swallowing disability.

Within the conceptual framework which arose from this study the essential concept framing operationalisation of family-based care to care-recipients with feeding, swallowing and mealtime disability as a result of MND was *protecting*, and the key processes associated with *protecting* were identified as *bearing, braving and persevering* and *watchful shepherding.* The frequency of the report of these concepts (or close semantic variants) within the wider body of literature on caregiving in MND, as described in chapter seven, emphasises the existential reality of caregiving in the context of feeding and swallowing in MND as consistent with caregiving in MND more broadly. While feeding, swallowing and mealtime challenges associated with MND are acknowledged to be inseparable from the illness itself, this study has provided evidence that all domains of feeding and swallowing impairment, including the psycho-social domains, can be profoundly impacted by this illness and warrant comprehensive and systematic attention in order to reduce the impact of third-party disability for family carers.

Evidence verifying the significance of adopting a social approach to feeding and swallowing disability, particularly given MND is a palliative illness in which family-centred care is paramount, has been provided in the presentation of this framework. Under-representation of the psycho-emotional and psycho-social outcomes of feeding and swallowing disability as experienced by family carers to date may contribute to an under appreciation of the extent of the role of these individuals and a reduced level of understanding regarding how the position of family carers may impact the choices and outcomes of PwMND. The results of this study draw attention to the assumptions and expectations that SLTs (and other HSCPs) can risk making regarding the role of family carers and how these assumptions may be misaligned with the expectations and preferences of the family unit.

While the conceptual framework arising from this study has been produced on the basis of findings reported for a collective of a (predominantly) white-Irish family carers, within an Irish health and social context, the key concepts identified as universally relevant for this cohort can sensitise clinicians, researchers and policy makers regarding the nature and extent of third-party feeding and swallowing disability. Given current literature available informing the family carer experience of feeding, swallowing and mealtime challenges in other cohorts does not contradict the relevance and applicability of the concepts uncovered as relevant in situating the experiences of family carers in this study, these concepts may tentatively be considered for their potential to generalise. The key concepts and relationships between the concepts of the explanatory framework may be useful to guide the design and approach to future studies which aim to verify these and build on the evidence base. Further studies of similar nature may broaden the applicability of these findings through providing an additional contextual balance necessary for progress towards the development of full theory. As further evidence in this substantive area builds on the foundation offered in the presentation of this conceptual framework, the ability to shape services more effectively and address family carer outcomes with needs-based, sensitive care will be enhanced.

10.6 Concluding remarks

To the researcher's knowledge, this is the only study to date which has used an explanatory approach to investigate the experience of family carers specifically with respect to feeding, swallowing and mealtime difficulties which occur due to MND. This is also the largest study of the mealtime experience for family carers of PwMND. Family carers, who are currently under-represented in general studies of dysphagia, were positioned at the centre of this inquiry from the outset as the researcher attempted to deepen the knowledge base and contribute to evidence-based care. The findings from this study validate the current body of research, which captures the wider illness experience of caregiving in MND by demonstrating that the magnitude of the psycho-emotional burden in MND can be contributed to in widespread ways by the many functional limitations this illness causes, including feeding, swallowing and mealtime difficulties. As evidenced in this study, the extent of the difficulties experienced by family carers may be actively hidden by family carers given their contextualisation of the feeding, swallowing and mealtime experience within the wider illness experience. The wider illness experience involves an ever present threat to the life of the family member with MND. Uncovering the extent of the disability, including third-party disability, occurring in the context of feeding,

swallowing and mealtime deterioration is required to inform the approach to limit the negative impact of feeding and swallowing disability on all who experience it.

Difficulties in self-feeding, eating and drinking which arise as a result of MND can significantly disrupt mealtime experiences. This disruption is apparent not only for the people who contend with self-feeding and swallowing difficulties firsthand, but also for family carers who provide the necessary supports to enable PwMND to navigate these difficulties during and outside of mealtimes. This study captured the depth and breadth of the disruption that feeding, swallowing and mealtime difficulties present for family carers and outlined the psycho-emotional and psycho-social consequences of same. In MND, we already know that family carers put themselves at high risk of psycho-emotional and psycho-social ill-health consequences, which can be protracted and prolonged as family carers live the illness alongside their family member with MND (Cipolletta & Amicucci, 2015; de Wit et al., 2019; Poppe et al., 2022). This study provides an insight into the compromises family carers can make to support their family members, not only to meet their nutrition and hydration needs but also the social and emotional needs of care-recipients related to eating, drinking and mealtime experiences. This study documents the relentless nature of the family carer role and extends the understanding as to how members of the wider family unit can be impacted by the feeding, swallowing, and mealtime-related changes brought about by MND. Understanding the extent of the impact that illness-linked consequences have on family carers is required to protect the health and wellbeing of these essential partners in care and ensure that home-based care is safe and sustainable for both members of the care dyad.

This study aimed to develop an in-depth understanding of the mealtime experience from the perspective of family carers of PwMND, and to generate a conceptual framework accounting for the mealtime changes which occur as a result of MND. Identification of the key processes which may account for how family carers engage with PwMND during feeding, swallowing and mealtime situations is necessary in order to gain insight regarding the obstacles and enablers in the successful navigation of changes in these areas within the care dyad. Key psycho-social processes underpinning family carer behaviour in the context of feeding, swallowing and mealtime challenges, previously unknown, have been identified and are presented in the conceptual framework representing the findings for this study. This framework can be used as a point of reference to understand interactions occurring between family carers and care-recipients when feeding, swallowing and mealtime challenges arise in the context of MND.

Knowledge regarding family unit-based changes occurring as a result of MND has been explicated in this study. The establishment of a care relationship alongside the traditional family relationship contributed to role, relationship, and identity changes and, in many cases, an altered power dynamic within the pre-existing family relationship. The psycho-social challenges of feeding, swallowing and mealtime difficulties, including these role, routine, and relationship changes, exposed care-recipient vulnerability and brought their physical disability, functional limitations, and risk for negative complications to family carer attention. Family carers mitigated current and anticipated negative sequelae associated with feeding, swallowing and mealtime difficulties on a constant basis through careful surveillance, which was both overt and covert. Family carers masked care-recipient disability in order to protect care-recipients, wider family unit members, and themselves from being emotionally confronted with the full extent of the illness.

Being able to understand the responsibility family carers experience to protect care-recipients and the wider family unit may enable HCPs who engage with families impacted by MND an opportunity to integrate this awareness into clinical practice. HCPs can be considerate of the sense of protection family carers experience through delivering care in a way which is sensitive to the operationalisation of protection by family carers. This study implicates important barriers and facilitators to informal family-based care in the context of feeding and swallowing disability, including the availability of supportive resources which may impact family carers' ability to manage the multiple competing demands and negotiate the co-occurring agendas of the numerous stakeholders in care (see Appendix O). As evidenced in this study, access to appropriate resources when navigating the often highly distressing emotional consequences of MND, including sadness, loss, anger, frustration, guilt, and fear, as well as social consequences, including role, relationship, and identity changes occurring within the family unit, may empower family carers in their caregiving role. HCPs have an important opportunity to support family carers in accessing appropriate resources that can reduce the risk and severity of negative sequelae associated with both family caregiving and with the psycho-social consequences of feeding, swallowing and mealtime impairment.

The conceptual framework generated in this study can be used to inform clinical practice. The study has yielded important knowledge regarding the direction of future research necessary to progress the family-based care agenda in feeding and swallowing impairment in MND. HSCPs such as SLTs require further evidence to enable due diligence in managing feeding, swallowing and mealtime-related sequelae. Currently, the physiological aspects of feeding and swallowing impairment in MND do not have clinical guidelines or consensus documents indicating management standards. Directions on the

management of the psycho-emotional and psycho-social consequences of oropharyngeal dysphagia in MND are even less apparent in practice-governing documents. Confidence in the actions of HSCPs may be enhanced with formal practice guidelines informing comprehensive care by addressing all domains of impairment in feeding and swallowing disability. Broadening the role of HSCPs involved in the management of feeding and swallowing impairment may be helpful to encourage the patient and family caregiver to remain engaged with services based on the premise that such services would have the capacity to comprehensively address the multiple components of care which pertain to feeding and swallowing, not just the physiological.

Mealtimes, the sharing of food, drinks, and the ability to participate in eating, drinking, and mealtime-based routines hold a deep meaning that extends beyond the sense of togetherness at a specific moment in time to include an individual's ability to orientate to their sense of self (Clarke et al., 2018). The framework generated in this study provides a foundation from which to understand and respond to the needs of family carers as they navigate the impact of MND on the mealtime experience within the context of the evolving disease trajectory. The in-depth, nuanced, and multi-layered perspective of third-party disability uncovered in this study makes a noble contribution to research. However, the significant amount of research attention that is required to comprehensively address family carer needs and optimise outcomes for family units impacted by MND should not be overlooked. This study indicates that the psycho-social needs of both members of the care dyad are complex. Disease-related factors such as feeding and swallowing impairments are unpreventable in the context of MND. Despite this, the existential meaning of the disease, as it encompasses all members of the family unit, requires foregrounding to ensure flexible, sensitive, and need-driven frameworks for healthcare are implemented as standard.

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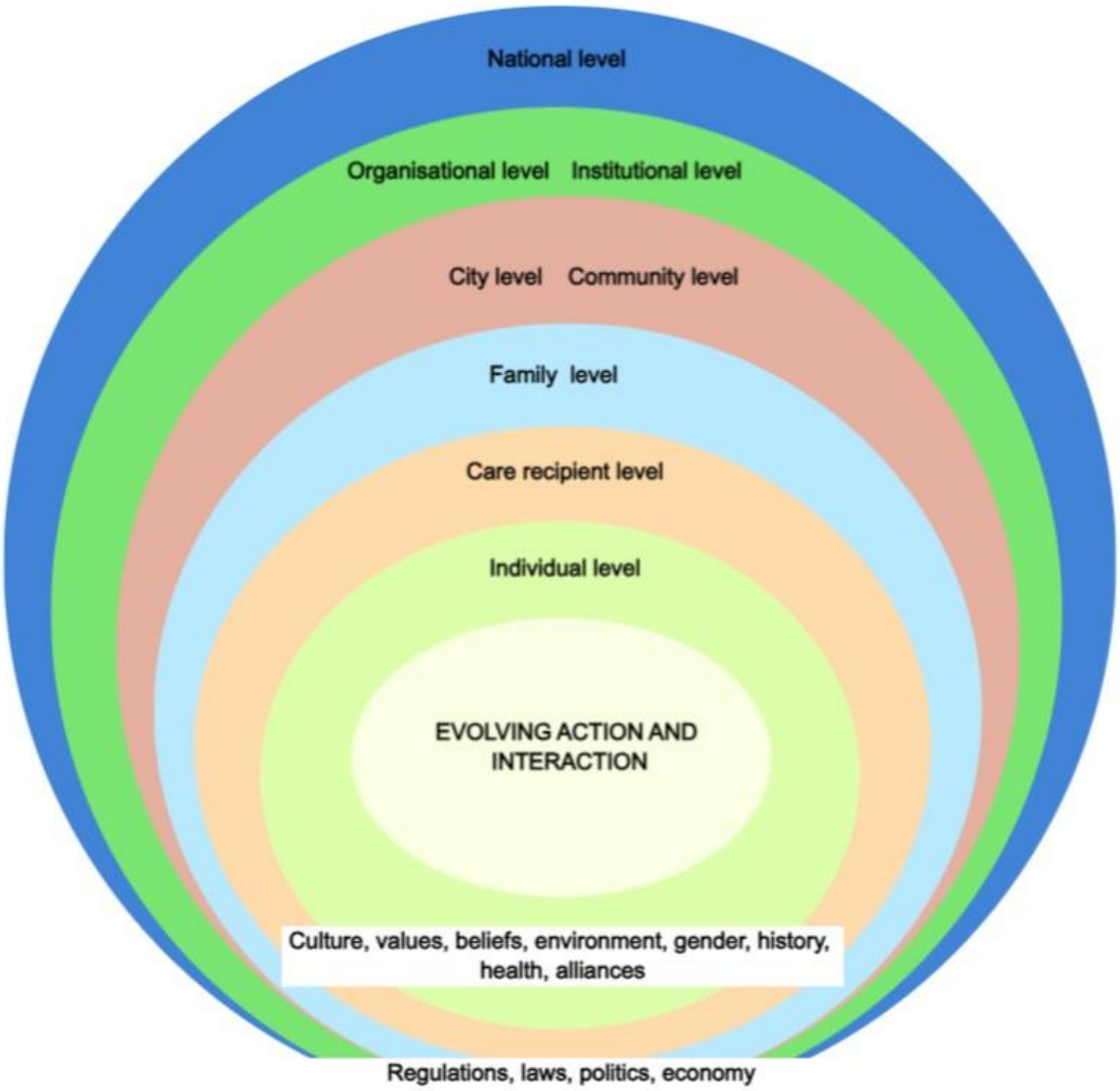
APPENDIX 'A'

CONDITIONAL/CONSEQUENTIAL MATRIX

(CORBIN & STRAUSS, 2008/2015)



Note. Adapted from *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed., p.163), by J. Corbin, & A. Strauss, 2015, Sage Publications Inc. Copyright 2015 by Sage Publications, Inc.

APPENDIX 'B'

CONSENT FORM

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTICS, SPEECH AND COMMUNICATION SCIENCES

Consent Form

PROJECT TITLE: An exploration of the mealtime experience for family carers of people with Motor Neurone Disease

PRINCIPAL INVESTIGATOR: **Stacey Daly M.Sc. (Trinity College Dublin)**
Clinical Speech and Language Studies

ACADEMIC SUPERVISOR: **Dr. Caroline Jagoe, Assistant Professor**
Clinical Speech and Language Studies

ACADEMIC CO-SUPERVISOR: **Dr. Geraldine Foley, Assistant Professor**
Occupational Therapy

I am invited to participate in this research project which is being carried out by Stacey Daly under the supervision of Dr. Caroline Jagoe and Dr. Geraldine Foley. My participation is voluntary. Even if I agree to participate now, I can withdraw at any time without consequences of any kind.

The study is designed to investigate the mealtime experience for family carers of people with Motor Neurone Disease (PwMND). If I agree to participate, this will involve me taking part in one individual interview lasting up to 90 minutes at a place of convenience for me. This interview will be audio-recorded.

I understand that the interview may involve unavoidable discussion of topics which may be sensitive. I have been made aware of available supports and agree to access these should I need support following my participation in this research.

Although I will not directly benefit from this research, the information obtained through conducting this study hopes to influence the way care is delivered to PwMND who experience eating and drinking difficulties in future. This study will also attempt to shape how healthcare professionals work with family members of PwMND who are experiencing eating and drinking difficulties.

I understand that the individual interviews will be audio-recorded and that in audio-recording the investigator will endeavour not to record any information that could be used to identify me. I understand that the audio-recorded material (and any notes taken at the time of the individual interview) will be stored securely during the data analysis process on a password protected computer, with the password known only to the lead researcher and academic supervisors. Original recordings will be deleted immediately once the information contained within has been analysed.

Any information or data which is obtained from me during this research will be treated confidentially. I understand that any information that could be used to identify me as a participant in this research will be stored separately from any other information collected and held in a locked cabinet that is not accessible to any person other than the lead researcher and the academic supervisors.

I understand that transcriptions of the audio-recordings will be coded to ensure I remain anonymous.

I understand that data from this research project may be published in future. Quotes used from my transcripts may be used, however these quotes will be anonymised. The original recording and all copies will be available only to the research team.

I understand that I may have access to any information held on me by contacting the research team (within a period of 5 years).

If I have any questions about this research, I can ask Stacey Daly via email sdaly9@tcd.ie or via telephone 087 228 9927. I am also free to contact Dr. Caroline Jagoe via email jagoec@tcd.ie or via telephone (01) 896 1496 to seek any further clarification or information.

Signature of research participant

I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the participant information leaflet and a copy of this consent form to keep.

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study.

---------- ----------

Signature of researcher Date

**Please note the processes involved in this study are GDPR/ Data Protection Act 2018 compliant; the research team involved in this study have completed training in Data Protection and this study has undergone a Data Protection Impact assessment.*

APPENDIX 'C'

PARTICIPANT INFORMATION SUMMARY

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Date:

Name:

Date of Birth:

Address:

Telephone contact:

Relationship to care-recipient:

Participant information leaflet reviewed:

Inclusion/exclusion criteria confirmed:

Most suitable day for involvement in an interview:_____

Most suitable time of day for involvement in an interview: _____

Current living arrangements:

Date diagnosis of MND was made for care-recipient:

MND type:

General medical status of care-recipient:

Swallow status of care-recipient:

Modified diet:_____ Modified fluids:_____

Alternative feeding:_____ Oral nutritional supplements:_____

Length of time spent in the role of carer (self-determined):

Current care requirements fulfilled by the carer:

Factors impacting experience of care-provision for the carer (additional responsibilities/ support available):

APPENDIX 'D'

POSTER

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Are you the **family carer** of a person who has been diagnosed with MND?

Do you provide **any assistance** to a loved one to help them eat and drink?

Are you interested in taking part in a study exploring your experience of mealtimes with your family member who has MND?

What does the study involve?

Participation in an interview

Why do this study?

This study will investigate your experience of mealtimes with your family member who has MND. Your participation in this study will help develop strategies that healthcare professionals can use in the management of feeding and swallowing difficulties (dysphagia) for people with MND and their families.

For more information about participating in this study please contact:

Stacey Daly
PhD Candidate
Department of Clinical Speech and Language Studies
Trinity College Dublin
sdaly9@tcd.ie
087 228 9927

This study has received ethical approval from Trinity College Dublin & Beaumont Hospital (Dublin)

APPENDIX 'E'

PARTICIPANT INFORMATION LEAFLET

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

SCHOOL OF LINGUISTICS, SPEECH AND COMMUNICATION SCIENCE

PARTICIPANT INFORMATION LEAFLET

PROJECT TITLE: An exploration of the mealtime experience for family carers of people with Motor Neurone Disease

PRINCIPAL INVESTIGATOR: **Stacey Daly M.Sc. (Trinity College Dublin) Clinical Speech and Language Studies**

ACADEMIC SUPERVISOR: **Dr. Caroline Jagoe, Assistant Professor Clinical Speech and Language Studies**

ACADEMIC CO-SUPERVISOR: Dr. Geraldine Foley, Assistant Professor Occupational Therapy

Introduction: You are being invited by the research team to participate in this project exploring the mealtime experience for informal (family) carers of people with Motor Neurone Disease (PwMND). Your participation is voluntary. Even if you agree to participate now, you can withdraw at any time without consequences of any kind.

Caring for people with MND takes a considerable amount of resources both physical and emotional. Family carers are crucial to the success of many healthcare professional (HCP) interventions for people with MND. The purpose of the project is to:

- Identify barriers and facilitators to the optimal engagement of family carers with HCPs
- Contribute to the body of knowledge on the impact of caring, specifically with regards to feeding and swallowing challenges which are associated with MND
- Explore how the experiences of family carers change over time
- Explore the impact of the caring process on family carers and PwMND to inform sensitive and relevant healthcare practice

Procedure: Your involvement includes participation in a one-off interview that aims to explore your experience of mealtimes. You can expect to be interviewed on one occasion only, for a time period of no longer than 90 minutes, regarding your experience of mealtimes since MND has entered your life. In order to be eligible for involvement in this research you must:

- Be over 18 years of age, English-speaking, and be able to give consent
- Identify yourself as a family carer of a person with MND (who has experienced changes to swallowing and/or feeding as a result of the onset of MND)
- Be able to participate in an individual interview that could last up to 90 minutes and involve discussion of sensitive information

The individual interviews will be held at a location of convenience for you.

Exclusion from participation: You cannot participate in this project if you are known to the lead researcher.

Benefits: The information gained through conducting this project is hoped to influence the way healthcare is delivered to people with MND and their carers in the future.

Risks: Whilst every attempt will be made to minimise discomfort during this project, the nature of MND means that there may be some discussion in the interview involving issues of a sensitive nature. The interview schedule has been developed in such a way as to minimise any discomfort for participants and you may choose not to answer any question you feel uncomfortable with during the interview process. Your wellbeing will be monitored at all times and will remain of paramount importance. The Irish Motor Neurone Disease Association (IMNDA) is available to support any participant who may require support as a result of participation in the project.

Confidentiality: Audio-recording of the interview is necessary to accurately capture information discussed. However, during audio-recording the lead researcher will endeavour to record no information which could be used to identify you. Audio-recordings will be coded for analysis to ensure your privacy is maintained. Once analysed, all audio-recordings will be deleted. Coded transcriptions of the audio-recordings will be stored on a password protected computer which will be accessible only to the research team. Any information which could be used to identify you will be kept separate from any data, and will be secured in a locked filing cabinet which only the lead researcher and the academic supervisors have access to, in the Department of Clinical Speech and Language Studies in Trinity College, Dublin. Although data from this project may be published/presented, your name will not be published and will not be disclosed to anyone outside the research group. Quotes from interview

transcriptions may be used, however these quotes will be anonymous. Your identity will remain confidential at all times.

Copies of information held by the research team relevant to your participation in this research may be provided to you on request by contacting the lead researcher (within a period of 5 years).

Compensation: This project is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Stopping the study: The lead researcher may withdraw your participation in this project at any time.

Permission: This research project has Research Ethics Committee approval from the School of Linguistics, Speech and Communication Sciences (November, 2015) and Beaumont Hospital (August, 2016); both bodies are updated with the status of this study annually.

Further information: If the research team learns of important new information that might affect your desire to remain in the project, you will be informed at once.

Expression of interest in participation: Please take your time to consider whether you would like to be involved in this study. You can register your interest in participating, get more information or answers to questions you may have about the project from:

Stacey Daly
Lead Researcher
Phone: 087 228 9927
Email: sdaly9@tcd.ie
Address: c/o Department of Clinical Speech and Language Studies,
Trinity College Dublin
7-9 South Leinster Street,
Dublin 2

Alternatively, Dr. Caroline Jagoe is available by contacting (01) 896 1496
or by emailing jagoec@tcd.ie.

APPENDIX 'F'

INITIAL INTERVIEW GUIDE

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Key interview question:

1. I would like to invite you to talk about your experience of mealtimes since/after MND came into your life.
   Probe:
   What does/did a typical mealtime look like/involve for you?
   Could you describe to me your best and worst mealtime experiences since/after MND began to affect your family member's ability to eat and drink?

Potential further lines of enquiry compatible with the scope of this research project - aide memoire

Can you tell me about your experience of feeding/swallow impairment?

Probes:

Experiences before MND?

Experience of diagnosis of the person with MND (dysphagia)?

How did you react?

What did it mean for you?

How did the feeding and swallowing difficulties progress?

Please describe your experience of the management of swallow impairment?

Probes:

Who is/was involved?

How is/was it important to you?

How is/was it important to the person you provide/provided care for?

What helps/helped?

What hinders/hindered your experience?

Can you describe some of the major challenges you experience/experienced in providing care for the person with feeding/swallowing impairment?

Probes:

Preparation of meals

Modification of diet/fluids

Monitoring intake of diet/fluids/medications

Negative complications associated with swallow impairment

The experience of mealtimes for you and your family

Providing assistance with eating and drinking

Ensuring safe swallow strategies are/were adhered to

Nonadherence/autonomy

Alternative feeding

Keeping up with changes

Impact on the experience of social occasions for you and your family

In general, are there any recommendations you could suggest for other carers of individuals with swallowing impairment due to MND?

Probes:

Is there anything that you know now that you wish you knew at the beginning?

In general, are there any recommendations you could suggest for professionals working with carers of individuals with feeding/swallowing impairment due to MND?

Is there anything else that comes to mind, which we have not yet discussed, that you feel is important to help understand what it is/was like for you to be a carer of a person with feeding/swallowing difficulties?

APPENDIX ‘G’
REFLEXIVE JOURNAL EXCERPT

I felt uncomfortable at times during this interview. The fact that this participant is young and has taken on the role of primary carer for her father was difficult to explore. I worry that this participant is vulnerable to poor outcomes regarding mental health; essentially this is the nature of the situation.

In reviewing the transcript, I feel I offered more support, acknowledgement, validation and reassurance than usual. I felt the sense of ‘unjust treatment’ strongly came through the informant’s account and it was hard not to feel personally conflicted by the tragedy described. The demands on this participant in the context of poor social, emotional and financial supports as well as limited life experience (on the basis of age alone) seemed particularly difficult to reconcile. This informant is experiencing a very high level of demand and is very fearful of the future; very overwhelmed.

APPENDIX 'H'
TRANSCRIPTION CONVENTIONS

Convention[1]	Meaning
-	Reformulation or restart
Wor-	Incomplete word
(.)	Barely noticeable pause (untimed)
(…)	Long pause (untimed)
word	Speaker emphasis
.	Full stop or stopping fall in tone
,	Continuative
#	Tone signalling uncertainty
…	Incomplete utterance
[word]	Overlap
(xxx)	Unintelligible passage
((sniff))	Non-verbal activity
(info)	Information from observational field notes/explanation relevant to context (e.g., clarification of pronoun use/topic)
>word<	Pace of speech has quickened
<word>	Pace of speech has slowed
↑	Rise in intonation
↓	Fall in intonation
WORD	Speaker raises voice / shouts
wo(h)rd	Laughter observed in the talk
::	Elongated sound

[1] Adapted from Jefferson (1984)

APPENDIX 'I'

METHODOLOGICAL MEMO EXCERPT

Methodological note: A review of the advancement of coding

Date: 13/02/2022

This memo was written during my analysis of the transcript from the 16th interview, Peter.

At this point, I am acutely aware that my analysis is at a more abstract level and more theoretically driven. I know this because I'm looking at saturating the properties of the categories I'm already aware of, expanding and refining the dimensions of these properties to make sure the findings are relevant and robust. In my analysis, I aim to capture all significant nuances which may impact interpretation.

Using the following excerpt I can affirm how my coding and analysis has evolved:

> "When this (MND diagnosis) happened we sat down and talked about it and we agreed that we would carry on as normal. And do everything we always done. You know. And I didn't know. I did notice that (…) she wasn't eating as well as she was. (…) We were in a situation where we were going out twice, three times a week for a meal. We can't do that now." (Peter, Passage 40)

At an <u>open coding level</u> I would have fractured this data into codes as follows:

Team working in the context of MND

Agreeing to maintain normalcy

Experiencing social limitations due to swallowing deterioration

At an <u>axial coding level</u> I consider the fit of this data in relation to the categories identified in the current explanatory framework:

Team working

I can attend to the utility of *teamwork* amongst the members of this dyad and the role of *teamwork* in the ability to protect *normalcy.* I note that for this participant, an overt discussion on how the illness would be approached (as a team) occurred between the two members of the care dyad. *Communication* as a important dimension of *team working* can be verified by this data. I consider this excerpt in the context of the transcription in full with respect to the dimension of *leadership* within the property *team working*. I want to gain an understanding of how the care dyads function as *team* and when/why changes within the *team* may arise (in the context of illness-related feeding and swallowing difficulties). I also

want to gain an understanding of what impact changes within the team have on the *balance of power* within the care dyad.

Team working has been identified as a property of the category *surveillance and judgement of feeding and swallowing situations.* In this excerpt, deterioration in the swallowing of the care-recipient is reported to have been noted by the participant, and the changes to *normalcy* based on the progression of the care-recipient's illness are explained. *Altered food and drink-related routines and rituals* are linked and can be understood as a threat to the *normalcy* not only of the care-recipient but also to the family carer's sense of *normalcy*. Changes to food, drink and mealtime-related behaviours that are meaningful for both members of the care dyad are highlighted here. The impact food and drink-related rituals have on social functions, how the team acts to *protect* important routines and rituals, and the success of this *protection* remain under investigation.

At a selective coding level I am interested in verifying the core category identified as most appropriate to offer an in-depth explanation of the experience of caring in the context of feeding and swallowing difficulties for the participants. Currently, the core category has been identified as *protecting*. I feel *protecting* is illustrated within this data excerpt as the desire to *protect what is normal* is foregrounded by the participant. My line of questioning (probing) in this interview was consistent with theoretical sampling; so I look towards the full data set for any evidence that would verify or refute *protecting* as the core category. In passage 76 of this transcription I asked the participant directly if the concept *protecting* resonated with him. The respondent verified the relevance of *protecting* by explaining that he actively sought to *protect the care-recipient's dignity* as he provided care and did so while at times *compromising* his own dignity. *Protecting dignity* is a subordinate category under the core category *protecting* presently. Theoretical sampling and selective coding are both apparent at this point in data collection, and I'm reassured that the analysis has progressed to this point. I'm reassured about how the study is progressing.

APPENDIX 'J'

THEORETICAL MEMO EXCERPT

Concept exploration: Feeling frustrated at care provided by health and social care professionals (HSCPs)

Date: 19/11/2019

This memo was written after my analysis of the transcript for the 6th interview, Fran.

In passage 186:

> "Well at the time it was frustrating. I remember Con going to the bother, in the hospital, of going to the bother of travelling into for an appointment with the speech and language therapist to be told that yoghurt would be a good idea (…) And that putting powder in water was a good idea. We just never…-I couldn't relate to that at the time."

There is an apparent link between the concepts *changing focus on food from quality to safety, focusing on loss related to FEDS impairment*, and *forced acknowledgement of disease progression with the onset of new symptoms.*

I feel this concept warrants further exploration. It has only been recorded once across previous transcripts in relation to speech and language therapy (SLT) management, and I wonder whether this is because it is an extreme case or whether it is relevant to all of the family carer's experiences, but that the line of questioning has not yet provided the opportunity for this concept to present. In this respect, the concept warrants interrogation in upcoming interviews.

In Fran, Passage 186, the participant is discussing how he felt when attending the SLT clinic with his wife and the "bother" it took to attend. This participant had previously explained that he and his wife had been made to feel "lucky" to be getting appointments with HSCPs because they were "hard to come by". The "bother" it took to attend the appointment was contrasted with the advice given by the SLT, which involved a recommendation to use thickened fluids and to modify the consistency of diet his wife was taking. The participant reported the advice from the HSCP was limited in relation to the breadth of the recommendations arising from the session (does this gap relate to an assumption or expectation regarding the role of the SLT and/or does it relate to the individual's priorities for care and a potential for misalignment there with the HSCPs goals?); inaccurate in relation to the risk identified (the SLT is inferred to have foregrounded the safety-related risk which could arise through non-adherence to modified diet and fluids rather than the potentially greater risk associated with wellbeing/psycho-emotional status threats that premature introduction of compensatory strategies for feeding and swallowing difficulties

may present); and unhelpful (further information is required here regarding the specific way in which the SLT input was unhelpful as this was not explored in detail).

> "She was always doing her own research so maybe it was a case that she was very often ahead as well, she would have done her background research and so on. When you get in front of a professional who then talks about 'Here's a powder that you are going to have to use' and gives you a box of it, there's just never any need to go there. At the time. But it's presenting a really bleak picture that isn't, that we hadn't reached at that point and she still hasn't reached."…"You're working with somebody to deal with things happening. As opposed to looking two three years ahead to something that might not happen." (Fran Passage 204/208)

In further discussion, the participant described care that was pre-emptive of deterioration as being unacceptable. The participant described the importance of hope when living with Motor Neurone Disease (MND) given the unavoidable losses associated with this terminal illness. Pre-emptive care for this individual threatened this sense of hope and appeared to impact the acceptance of the illness (in general) as well as the acceptance of the deterioration that it was causing (deterioration of function).

Although the perspectives of SLTs who work with people with MND (PwMND) and their family members are not under investigation in this study, I am wondering what the SLT aims were here and whether there was a particular structure to the decision-making leading this clinical intervention. I wonder broadly about risk and whether a potential risk to physical safety was considered more of a concern than the risk to wellbeing/optimism for family carers/PwMND. I wonder whether there are circumstances where pre-emptive care is more or less acceptable and what influences this acceptability; certainly, in the case of gastrostomy insertion, forward planning is often essential to ensure candidacy. Are there important differences in this specific scenario?

I am aware of the wider literature in MND relative to *living in the moment*, but this interview has given me a new perspective on the importance of that concept and how this could be a contextual condition linked to family carers' engagement in feeding and swallowing interventions. I'm wondering whether introducing changes early in the context of an irreversible illness may critically impact clinical relationships. I also wonder how SLT recommendations may be supported or rejected by family carers of PwMND under certain circumstances, and how powerful this might be for HSCPs supporting PwMND.

Potential areas for theoretical sampling

- How are feeding and swallowing recommendations introduced? What factors contribute to this as a positive experience, and what factors contribute to this as a negative experience?
- Do changes with feeding and swallowing recommendations have an impact on the family carer's sense of hope, view of illness, or family dynamic?
- What are the additional risks of pre-emptive care, and under which circumstances is pre-emptive care warranted?
- What makes it easier/harder to follow the advice of HSCPs in the management of feeding and swallowing difficulties?
- What factors contribute to whether modifications/adaptations/compensatory strategies are considered acceptable or not by family carers of PwMND in the context of feeding and swallowing difficulty?

I am interested in addressing some of these questions in upcoming interviews.

APPENDIX 'K'

TRANSCRIPTION "TONY"

Length of interview: 1h10min
Note: This interview initially took place virtually using BlueEye platform. Multiple breaks in the interview occurred due to poor Wi-Fi. The interview restarted and eventually transferred to mobile phone platform, where the participant consented to audio recording of the speaker phone interview. Although the interview was disrupted at times, the flow quickly recovered and did not seem to impact the information exchanged.

Turn	Speaker	Passage
1.	**Researcher**	**So Tony I have a list of questions but what strikes me from our earlier conversation was the changes you as a family were confronted with as your wife's illness progressed. And I just wondered if you could start by explaining to me how those mealtimes changed for you?**
2.	Informant	I suppose before Niamh got sick breakfast would have been a mealtime where Niamh was making sure the kids got fed so it was never a time where we would have sat down together and that continued with Niamh. What it meant for me as the illness progressed, it was more me trying to have something that I could eat while I was feeding Niamh so that I was trying to manage time, always trying to manage time. In that if, I never really had time to sort of feed Niamh and then sit down and eat myself because the kids -were trying to get the kids out to school and all that. So all that was going on, most of the time we will say for most of the year during the school year and stuff like that. So. Breakfast changed that way in that it was something that I suppose as Niamh's ability to eat and swallow deteriorated it was more fluids maybe some porridge or up to a certain point she was able to eat maybe a fried egg but then it got too difficult to break up the fried egg in her mouth. Then we moved on to porridge which is easier for her to digest or to eat, to swallow really. I don't think she was eating she wasn't swallowing if you know what I mean. Then on to the Fortisips and Forticreams. So breakfast for me was having ((laughing)) having a coffee, having a coffee and a fried egg and something, balancing it on my lap while I was trying to feed Niamh. Lunchtime was similar but it was quieter because the kids wouldn't have been there, they would have been in school. At the weekends, it was pretty much the same. Dinners, we always tried to sit down together as a family for dinner and I think up until maybe a year ago we still managed to do that where everybody, the kids organising stuff as well, helping me to organise and getting -everything was sorted in the kitchen as such, food was ready to go and then we will say "We will bring Mom out." And then Niamh was brought out. She was able to sit in the chair until a few years ago, I don't have the time frame now. It would have been her always on my left because I could never feed her sitting on my right. Little things like that became more of a routine once we figured it out. You know I always had to feed her over my left shoulder.

		So it was like, I would feed her, I would eat, I would feed her, I would eat and we would be chatting. And then the lads, the mealtimes were us sitting around the table as much as possible, certainly at the weekends was as much as possible as we could. We got on with it really.
3.	**Researcher**	**The importance of that dinner time together, was that always something that you did in your family? That sense that you didn't want to disrupt that dinnertime, was that always important in your family?**
4.	Informant	I didn't get that, it was breaking up (referencing the Wi-Fi connection)
5.	**Researcher**	**I just asked about the dinner times and the importance of you maintaining that under really difficult circumstances, was that always something you really valued?**
6.	Informant	Yes. Yes. I think not just mealtimes right. Pretty much everything. We are a very close-knit family, we did everything together, the lads knew what was going on and never just…-just got on with things really. The kids were great that way anyway to be fair, the lads were anyway and it's what Niamh wanted as well. It was just the way we approached things. We did a lot, we did pretty much everything together. Even before Niamh got sick, just to give you an example of our approach, you know we would come up to an anniversary, a wedding anniversary or something like that you would kind of say "We should do something ourselves on our own" but when it come to that we couldn't do that ((laughing)).
7.	**Researcher**	**You couldn't get rid of them? ((laughing))**
8.	Informant	We didn't want to, you know what I mean. It, we would just go out for a meal and that was it and we would sit around and could spend two hours there or three hours there just chatting away and that continued because maybe that was the way we started out with them and that was what the lads expected or that was what we wanted ourselves, it was just that natural way for us to do it and that is what we did.
9.	**Researcher**	**People have explained that maintaining that routine is so important.**
10.	Informant	Yeah.
11.	**Researcher**	**I suppose those things seem like the things that people make multiple sacrifices to do and you were talking about Niamh's chair to support her you would bring that in and you would do these things to accommodate that, I just wonder in terms of the role of that mealtime within your family did you have or was there ever a parenting aspect to that too? Sometimes with the teenagers it's hard to, I imagine it's hard to get them sat down and to be chatting about different things too you know. I just wondered**

		whether it was a purposeful thing within your family that you had in the back of your mind from a parenting point of view that that allowed you to do that in a really subtle way?
12.	Informant	Maybe but that would have been before Niamh got sick. So it wasn't a case of we didn't do it before and then Niamh got sick and then it was a case "Okay we have to start doing this" it was the natural way we always sat down for dinners and mealtimes and even since after Niamh passed. Lockdown helped us a small bit but that continued even though Niamh wasn't there and we sat there for an hour, two hours, three hours at times chatting away and Niamh was always included talking about memories passed and stuff like that. So yes you are right but it wasn't something that was introduced because of the illness, it was there before and we just kept going, we didn't try to…-we didn't give up and say "This is too hard."
13.	**Researcher**	**No. You would do whatever you could to accommodate that. That was very important.**
14.	Informant	Yes, and even when it did get hard, and it was getting harder and harder but maybe on a Saturday evening if there was a match on we were watching we would say "Look we will eat inside in the sitting room" and bring it in and eat on their laps and Niamh would be there and the fire would be on and someone would forget to bring in the salt and somebody would be giving out or whatever ((laughing)). It wasn't always everybody out to the kitchen table, it was where ever the time, the main thing was that we would try to be together.
15.	**Researcher**	**When we were talking earlier you mentioned Niamh's resistance to the hoist and I just wonder with Niamh was she, very early she was reliant on you with her arms to assist with feeding, I just wonder whether in the very early days when, was she ever introduced to adapted cutlery or cups or those kinds of things?**
16.	Informant	She was yeah. They didn't really work for her because it was down to her grip, I know they were adapted but she couldn't really grip them. If she could have, she would have because it would have maintained her independence, I know that okay. She didn't resist that at all if that was going to maintain her independence she definitely would have but it didn't really work for her.
17.	**Researcher**	**And how did you feel when those things were being introduced?**

18.	Informant	Yeah, it's (…) tough, yeah. (…) Knowing that it wasn't going to work but at least trying it. Thinking in my own mind, you know we had great support locally from the OT and speech and language as well and the public health nurse, they were brilliant. I know they were doing their best and they would say "Look let's try this." I suppose this was the first real sick…-the first real sickness that I have ever dealt with, that Niamh had dealt with, that anybody in our family had dealt with. There was no serious illness or sickness that anybody had dealt with before so we hadn't a clue ((laughing)). We didn't know what was…- whereas the professionals did, they knew what was happening and whatever was going to come along at whatever speed it was going to happen, it was slow enough for Niamh it started…-when something like that started to come in it was… -your mind starts to wonder and it was tough. Really, really tough.
19.	**Researcher**	**So is there a way that healthcare professionals could manage that situation that could be helpful for someone in your circumstance?**
20.	Informant	I suppose it's easy to say it now and it wasn't just for back then it was for the following four years, it was…-I suppose it's difficult from their point of view as well. It's a horrendous illness, what it can do and what it does do to the person that has it and the people caring, family, extended family and what they are looking at right so there's a balance to be achieved and I can understand that. To me as being the main carer, I ↑think I was the main carer for Niamh, to take me away and sit me down and tell me exactly what was going to happen and what she was going to need would have been very difficult. So I think maybe I needed somebody else with me to help who was maybe a little bit separate or a little bit more (…) whatever that supervisor would be that could give that information a little bit more to them.
21.	**Researcher**	**So is it because there is so much at the time that, and because you were going through…**
22.	Informant	(…) You broke up a small bit there (indicating reduced quality of Wi-Fi connection)
23.	**Researcher**	**I was wondering whether when these things were being introduced and explained to you, was that how it happened that you were separated from Niamh and had an isolated conversation, was that what happened?**
24.	Informant	No, not really, No.
25.	**Researcher**	**(Wifi connection drops- re-established after 4 minutes)** **So I was just trying to get my head around what you were explaining. So when the equipment was being introduced and even back to the beginning for you to be able to**

		understand what the illness was going to be like in the future, so are you saying you weren't given the opportunity one to one without Niamh there to speak to health professionals?
26.	Informant	It wasn't offered, if I lifted the phone and rang the MNDA nurse that support would have been there. But I didn't and I don't know why I think we were…-I don't know whether it was our approach we had the elephant in the room as such but life went on. I think it was more down to Niamh's approach if you get me. Niamh never…-we never sat down…-and I was only thinking about this recently when I was speaking to somebody else about it. Niamh never sat down or we never sat down and sort of queried what was going to happen and what was going…-she didn't really want to know, maybe it was Niamh's way of dealing with it and I was fine with that. We -as issues arose we dealt with it. It wasn't a case of we knew what was going to happen. Not that you could say what was going to happen in six months. It is hard to predict how the illness progresses anyway but I suppose we didn't have that picture into the future of what was going to happen in future "Oh, we are going to end up in a wheelchair. We are going to need the feeding tube." And all that. We got the information in the booklet from MNDA Ireland when we after the diagnosis and when we registered and I remember Niamh never really wanted to go, she never really asked what was in it and I sat down and I looked at it and I thought "Oh Jesus, no way." And I put it away. Obviously years later I picked it up and I was like well obviously that was what they were talking about there when I read this three or four years ago. So I think, I'm not saying we weren't given the opportunity because people were there to talk to but I think it was our approach as well, Niamh's approach was she just wanted to live. Okay we had to put up with it, but she wanted to live.
27.	**Researcher**	**You were saying if there was somebody with you when you receive the news who was less emotionally connected, I don't know whether you mean a case worker or somebody in the family who is not immediate family that might, if we could offer rather than wait to be asked, because you are just so overwhelmed, you don't know. And also you don't really know who is who on the team early on.**
28.	Informant	Yeah. I'll give you an example of when that really worked. The hospice here, when they came on board, I was dealing with a counsellor in there so they came on board I'd say a couple of years ago. Every three or four weeks I was meeting a counsellor because there was so much happening and so many changes Niamh was going through at that time, the disease was starting to really take hold. There was so much going on that I didn't really know about. They came on board and I went, I went in with lots of questions for example when Niamh was… -she was introduced to a feeding tube in the

		hospital and Niamh said “No.” She didn’t want it, she didn’t… - her attitude was she enjoyed her food and she said “Everything else has been taken from me. Are you really going to take away my ability to enjoy my food?” That was the way she approached it. I had worries about that at the time, it was getting difficult for her to open her mouth to get the food in so I had questions “What is going to happen when she can’t open her mouth? Will that happen? Will she choke?” I couldn’t talk to her about it. So at the time I was going into the hospice and I had those questions I could talk to her.
29.	**Researcher**	**How did you feel talking about those things, knowing that…-were you a little bit torn between the role of the husband and the role of the carer?**
30.	Informant	Yeah. Yeah. Yeah. In my mind I could see what was going to happen and how difficult it was going to get, and myself and Niamh she just wanted to continue as normal trying to eat how she did but the flip side of her doing that, thinking some bit ahead at this stage how difficult it was going to be and what problems it was going to cause. Yeah. It became (…)
31.	**Researcher**	**It’s difficult to imagine.**
32.	Informant	There was a couple of occasions Sunday dinner when there was episodes of choking. I thought it was choking, it was explained to me then that it wasn’t choking but I was afraid she was going to choke. There was one or two times it got caught in her throat. It wasn’t nice at the Sunday dinner, and then you look around the table and all the heads are dropped down because it wasn’t a nice picture for them (referencing dependent children present).
33.	**Researcher**	**That’s a very difficult dynamic because you are the husband in that moment, the father and a carer. There just sounds like so much going on in that moment.**
34.	Informant	Yeah. As I say in the early days of the disease it is overwhelming but that amount of information that you need is not as much as it was towards the end. That support that I had from hospice kept me sane. So something like that maybe back in the early days of the illness as well.
35.	**Researcher**	**Just to open the door. It can be hard because in the early days for family members who would be in the caring role to see themselves as carers too there can be resistance. There could be that too. Did you ever go through that?**
36.	Informant	No. No. I don’t think so.

37.	**Researcher**	**I wonder is that because Niamh had a physical need that was obvious, so if you have a limb onset it is clearly visible that you need help with buttons, you need help with cutlery, you need help with socks so you can't deny it whereas something with the swallow is more hidden?**
38.	Informant	Yes, that's what I was going to say. It was almost, it was a gradual process, the help, you didn't notice it day by day and because you didn't notice it day by day after within three or four or five or six months all of a sudden you are dressing Niamh in the morning from helping with socks.
39.	**Researcher**	**Did you have out of body experiences where you were thinking "What is going on here?" Because when you start a procedure you are in the middle of it and there is so much going on, especially with the mealtimes when you've got the kids and all and you are watching because you are worried about choking and I image there to be a lot going on.**
40.	Informant	Yeah.
41.	**Researcher**	**Are there moments where you step back and say "What is actually going on here?" or do you try and prevent yourself from doing that?**
42.	Informant	I didn't do that. I would have got times of anger. Not…-it was anger at the disease and what it has done. We will say it might have been a day where it might have been particularly difficult for Niamh to eat something, and that happened. There were some days where it was difficult and some days where it wasn't. It was strange that way. I would get so angry at why this disease is doing this? Why are we at this? Why? It's such a simple question but there is no answer to it. And Niamh used to be apologising then she would say "I'm sorry." I would be trying to say "It's not you, it's the disease." She was blaming herself. Niamh rarely blamed the disease, she blamed herself. But I didn't. Never.
43.	**Researcher**	**That is heartbreaking.**
44.	Informant	Yeah. There were moments like that alright. There were moments also where Niamh wanted to end it she wanted to you know. She had had enough.
45.	**Researcher**	**Yeah. Yeah. Okay (.) I guess going back to the progression of the illness. Did it make it easier or more difficult the slower progression versus the more rapid deterioration?**
46.	Informant	(…) It's many years now since Niamh had her first symptoms. Those years were okay, my life went on, and then we had the diagnosis. In the early days life was good, life continued, we managed around it we worked around, any time there were changes we adapted, the adaptations we had to make over the

		last number of years were huge. We still went on our holidays, we still went abroad since her diagnosis, it was tough but we managed it. So the slow progression from that point of view helped until a year ago, at the end of the slope it is very difficult. It's a cruel thing to say I suppose. It is inevitable what is going to happen but (…) it just made it very difficult. It was incredibly difficult. Over the last year. The slow progression gave us the extra years but at the back end of it it was very difficult.
47.	**Researcher**	**Was it because of fear? That you know what's around the corner and you are just so fatigued with preparing yourself or is it that her quality of life had got to a point where you just didn't feel it was that she had good quality of life, or was it your quality of life. I mean you weren't eating, you probably weren't sleeping, you weren't able to do I'm sure many things to manage stress. Did it just get to that point where you thought "I've tried my best"?**
48.	Informant	Yeah. It was her quality of life was the main thing. But I think as a carer that is what you do. You put yourself second. But yeah it was down to her quality of life really.
49.	**Researcher**	**Just in terms, I know you were saying around the mealtimes the whole ritual starting in the kitchen, you mentioned with the Sunday dinner- the preparation. Before she got sick would that have been Niamh's role primarily or would you have both been involved in all that preparation and cooking? Was that shared?**
50.	Informant	No Niamh stayed at home, she was a home maker and she wasn't working, she hadn't worked for however many years and she wanted to stay home with the kids and I was quite happy with that. So that was great and I was very happy with that. So was it, it was probably seventy thirty, Niamh looking after the home before she got sick. Maybe eighty.
51.	**Researcher**	**When that changed was that difficult, that kind of takeover, you had to take over those roles, was that a difficult thing to navigate?**
52.	Informant	No (…) more no than yes if you know what I mean.
53.	**Researcher**	**Why?**
54.	Informant	I suppose we just got on with it. I haven't really thought about that. It just evolved. I don't know. That's a good question.
55.	**Researcher**	**We can come back to it.**

56.	Informant	No. It was like, it was almost like everyone stepped in, the lads and all, everybody stepped in. They prepared the veg and they prepared the potatoes and spuds, whatever. I'm trying to think now. I can only remember recently, I can only really remember the last year or so because it was so busy, so blinkered it was so full on, so all in. What happened beforehand it is only starting to come back to me.
57.	**Researcher**	**It seems so far away now.**
58.	Informant	It seems so far away.
59.	**Researcher**	**The children, when they were helping with things, did they ever assist Niamh to eat?**
60.	Informant	Yeah they would have, but it wasn't a case of "It's my turn today to do it and it's your turn tomorrow." I never approached it that way. I didn't want to. It was if you sat in beside Niamh or if I was late home from work and if Niamh was hungry and she wanted somebody to do that she asked for it. I know one of the lads did say to me recently, he said "There was times where we were praying for you to come home because we didn't want to, because it was so difficult to do the feeding." But yes they did in terms of giving Niamh water and all that but if they didn't do it, if I came home and it wasn't done I wasn't going to get upset or complain because I knew how difficult it was. And I didn't want that…-that is not a memory you want as a child. Remembers feeding his mother because she couldn't. But at the time they were happy to do it and did it but it was never forced on them. It was more of a natural thing, I'm sat beside Mom and she needs this, I'll give her that. It wasn't like "I need a break, you do it. I need a break tonight, you are doing it."
61.	**Researcher**	**So for you what was that about? What did it mean to you that you didn't ask them?**
62.	Informant	I just felt it was too much to put on them. It was hard enough as it was. And I suppose it was maybe, I didn't see it as my sole exclusive job that I didn't want anybody else doing it, that's not why it was…-I just didn't want in ten or fifteen years' time that they might think "Dad has forced us to do this and he forced us to do that." Or "I had to do this." Or "I had to do that." I preferred it to be "I did this for Mom, this is what I had to do and this is what we did as a family." I think that might work better for them in the future. Even, it's just not fair anyway to be…- it's not where we should be. It is not the right thing in life that a child should be feeding their mother I think.
63.	**Researcher**	**Did Niamh ever have any conversation around that specifically?**
64.	Informant	No.

65.	**Researcher**	**Were there things that you noticed with the progression of the illness, say for her going from foods being chopped to going to more pureed foods to the reduced mouth opening and your concern about choking. When you started noticing those things, did you ever feel a sense…-were you ever apprehensive drawing attention to those things or…**
66.	Informant	Yes. I just did it. There was no major discussion. Again, as I say it was slow progression from just putting socks on to dressing Niamh over a number of months, it was the same for food. It was like mashing food… (Connection drops and there is a two-minute break; the interview continues later on speaker phone given consent)
67.	**Researcher**	**So you were saying the mashed in the same way as the physical needs around the dressing were slow. So it wasn't that you ever had a conversation around…**
68.	Informant	No it was…-look I'd have been thinking ahead I think and how to make it easier really. When I started to use the Nutribullet towards the end I would have been thinking "Let's try this today and see what happens." That sort of a way, not to make too much of an issue about it. So that was it.
69.	**Researcher**	**Was there ever a time when health professionals gave advice, I know you were saying around the PEG (percutaneous endoscopic gastrostomy) tube or the alternative feeding, I guess when that was originally discussed was Niamh always quite adamant that she didn't want to go down that route?**
70.	Informant	Yeah.
71.	**Researcher**	**But you felt a little bit different about it?**
72.	Informant	Yeah, I did because the feeding became so difficult. We could have those choking episodes, not that it was every week or anything like that but every so often that didn't help especially when the lads were around and seeing all that. But I had huge concerns over… -to feed Niamh you had…-I developed a routine, I was using a spoon, the food would be on the spoon and the first thing I would do was almost push her mouth open, push down on her lower teeth to get her mouth open and then get the spoon in as fast as I could. Often times her mouth would clamp and the spoon would get caught in her mouth and I would be afraid we would break a tooth. So I had concerns and there was a couple of times I raised…-I think it was after it was initially introduced to Niamh in the hospital we came home and we thought about it. At this stage Niamh was using the eye gaze (device) because her voice was gone. If Niamh typed up something on the eye gaze she meant it because she had to type it with her eyes. She typed up that she didn't want it, she

		wanted to keep going, she wanted to keep eating. I accepted that at the time but over the next couple of months or so as her ability to eat deteriorated I brought it up with her once or twice again and it became like touching a hot frame in an oven. It was like war with her almost, she just did not want it.
73.	**Researcher**	**And how did that feel for you because I guess your concerns for her were really around her safety, were you very worried?**
74.	Informant	Yeah. Yeah. So at the time I was getting support from the hospice, so I was able to talk to the experts in there as well so they helped and that's what helped. But there was no moving Niamh really. Until she was in the hospice then she asked the consultant if it was too late for the feeding tube, and it was too late at that stage.
75.	**Researcher**	**Really.**
76.	Informant	It was too late at that stage.
77.	**Researcher**	**And how did that feel for you then because you had been saying all along "Can we think about this a bit more." Was that really difficult to hear?**
78.	Informant	Well I knew that, I knew what the answer to that question was so I had been prepared I think, I knew. Yeah. What they said to her didn't come as a shock to me. It came as a shock that she asked because she had said nothing to me. So it was, it was an incredible worry.
79.	**Researcher**	**With those events, with the choking and as you said you looked around the table and your children's eyes weren't looking, were there things, were there other instances where that would happen routinely or was it just around choking?**
80.	Informant	No it wasn't. Niamh got up every day, she never said "No I'm not getting up today." The only day she didn't was the day she passed. So she got up every day so this was the way she approached it. There was bad days obviously where she got quite upset and tears in her room and she's just having a bad day and they knew that what was going on but it was rare to be fair. It was rare. But can I say that Niamh made it easier to deal with the illness with her approach? I think so.
81.	**Researcher**	**Do you think you made it easier with yours?**
82.	Informant	No, Niamh made it easier with her approach.
83.	**Researcher**	**I know but I wonder if you were a different personality type would you have found all of this a lot more…-what I am hearing is that you are very practically focused and I get the sense that you, your ability, and I'm sure it's not as**

		straight forward as this but your ability to accept her needs and wishes came first and you were satisfied with knowing what she wanted even though it wasn't always maybe what you chose for yourself. I am wondering about your sense of control and because I know in other families there are different levels of control that people might have in different relationship dynamics and I just wonder were those personality factors helpful for you?
84.	Informant	Maybe, yeah. I would agree. I think it was, I approached it very practically in terms of "How do we?" Rather than giving out about "Oh the eating is worse." That was going to happen, there was nothing we could do about it, so it was "What can we do to make it easier? Can I do anything? Can I adjust something." There was a lot of that going on. In my job I need to be very solution-focused dealing with practical problems day to day. I try to fix things and improve things and I think that helped. Another thing as well with the technology, the eye gaze, the power chairs if there was anything happening with them I had the confidence to fix that stuff myself. I think that helped as well. I was able to get things back up and running very quickly.
85.	**Researcher**	**You felt you had really useful skills.**
86.	Informant	Yeah.
87.	**Researcher**	**That's really good. I wonder around your sense of protection, it sounds like you were protecting your children a lot with this very careful navigation of being home late but knowing Niamh might have needed a drink of water or something like that but being very careful not to have an expectation on your children. Do you feel that concept of protection reflects how things were in general with Niamh and with your children, is that a fair concept to apply to your family and the way you were with them over that period of time?**
88.	Informant	(…) I think so, without forcing it, it was kind of the natural way of approaching it I would say. I wouldn't say, we didn't set out ground rules, we didn't set out requirements, we didn't say "Well this has to be done, you have to do this and you have to do that." It was like if I needed help I would call the lads "Could one of you help me?" Someone would come, you know that sort of a way. But at the end of the day it was me that was managing it and driving it and making sure it was done. And I suppose looking back, I was happy enough, obviously happy enough to do it and did it, I was able to do it. I was able to keep going doing it because it was difficult for so long. But obviously I was trying to keep the family together as well. And we did. We had good memories and good moments. You know I think our approach worked well. I wouldn't say Niamh and I sat down and said "This is how we are going to approach it." I suppose

		that was just the way we had done everything even before she got sick. And it continued.
89.	**Researcher**	**If there was something that happened, say there was a choking event, afterwards with your children did you try and minimise their emotional response to that? Did you try and follow up with them at a quiet time?**
90.	Informant	Yeah, yeah, yeah.
91.	**Researcher**	**So how would you do that?**
92.	Informant	It was just you know I wouldn't go to each one of them individually. They might… -Niamh might have gone to the loo after dinner and they might be in the kitchen tidying up and I would go out to them and say "Look lads are you okay? Any issues? You know why this is happening?" And they were fine you know. That was my approach. More often than not, all of them together.
93.	**Researcher**	**When that final discussion came up about the PEG tube, what is the significance of that in terms of how you see that illness pathway? Was that a turning point for you or not really because that had come earlier when you had first been introduced to the idea?**
94.	Informant	About when we were introduced to it in the clinic?
95.	**Researcher**	**Yeah or the final discussion when Niamh was wondering again about it and that came as unexpected to you. Do you see those as milestone moments in the way the illness progressed or are they just part of a big bag of things that were happening at the same time because other physical things were happening at the same time?**
96.	Informant	Well I think the feeding tube when it was first introduced to us I didn't understand as in how, the professionals introduced that to us and they knew what was coming I guess. That was certainly a milestone moment. ↑Did I know that at the time? I'm not sure. When Niamh asked for it recently, was that a ↑milestone moment? It certainly was because it was the last throw of the dice. She didn't survive much longer after that. I don't know was it a milestone or maybe a realisation in Niamh's mind. I'm not sure. She didn't say to me. It's not for everyone but that was her approach and that's what she wanted. I went with it.
97.	**Researcher**	**Were you ever in a situation where Niamh wanted something that you felt would be a choking risk? That you were uncomfortable giving to her?**
98.	Informant	Yeah. Yeah.
99.	**Researcher**	**Can you describe a situation where that was a problem?**

100	Informant	(…) She might have wanted… -it wouldn't have been the main meal because I would have been able to manage that and she would have known what way it was going to come to her and what way she was going to be eating. But maybe if it was a sweet she would have wanted a sweet or something like that, a hard, sucky sweet as she used to call them. And she would have wanted one of those. And I would have said to her "Look, that could be dodgy, that could go down the back of your throat". You know. "Are you sure?" So there was a couple of occasions like that. There were lots of occasions actually this year when she was in the hospice and it was difficult for her to drink the water, she couldn't use the straw to suck the water up so what she was doing was eating ice cubes. She was taking ice cubes in her mouth and that was also…-not just me but the staff inside and friends visiting at the time, she was adamant "No, I want ice cubes. I want it. I want it." So we had to give it to her. We told her it was dangerous "This could go down the back of your throat." She didn't care.
101	**Researcher**	**For you then, because she was physically dependent on you did you ever feel completely petrified that you have given her something now that…-do you sit there and watch her like a hawk, do you walk away? What do you do?**
102	Informant	No. No. No. You sit there and wait and watch. Yeah. Yeah. Yeah.
103	**Researcher**	**And in that moment is it just complete fear?**
104	Informant	Yeah. Yeah. Yeah. It is. Yeah.
105	**Researcher**	**Are you angry then because she has put you in a situation where you have had to do that?**
106	Informant	Not with her. No. Not with her. With the disease yes, but not with her. Sometimes it's hard to separate that.
107	**Researcher**	**I guess that's a pressure point for people who are dependent for feeding but are completely cognitively intact and that you are there going "I don't know what I am actually supposed to be doing here."**
108	Informant	Yeah. Yeah.
109	**Researcher**	**There's no real direction around that.**
110	Informant	No, but the person who has the illness is directing you. There has been so much taken away that you don't want to take that as well.
111	**Researcher**	**And is the whole thing in the back of your mind is that around maintaining or maximising quality of life, is it around protecting dignity, is it around protecting yourself**

		as well as protecting them? In those challenging moments what is the key thing you hold onto to help with your decision-making?
112	Informant	It's quality of life but it's also trying to protect the kids from what was going on. I think that protection of the kids became stronger as the disease progressed because it became so much more difficult. I stopped working and I had most of the last year with Niamh and I took on an awful lot more. Without actually sitting down and making that decision, that was forced on me by the disease itself, the progression. I think I was trying to protect them and keep them away, and keep their life going as well because Niamh's care became just twenty-four seven.
113	**Researcher**	**It sounds very, it's just such a difficult thing to navigate in so many ways. In that line is there anything that you would like healthcare professionals to know?**
114	Informant	The feeding tube. I've been thinking about this as well. Maybe I put too much emphasis on it in my own head, not to Niamh but maybe I kind of felt the importance of it was higher. The importance of it was more than -in my mind was more than what it was to Niamh. Niamh wanted to continue in feeding and eating by mouth, which she could still have done. I'm not sure if we could have done better around that, more information. It was done in a clinic situation in the hospital. Would it be better if someone came into the home and had more of a general chat about it and I wouldn't say try to scare or frighten Niamh into it or anything like that but maybe the whole… -the way it was introduced maybe the setting could be changed and maybe a bit more information but how you do that is different for every case. That's the only one thing that we could have done a little better on.
115	**Researcher**	**That's really valuable.**
116	Informant	That's the one thing in relation to mealtimes. The other thing, I'm not sure if it is related to your discussion but the Nippy, the ventilator was introduced to us but Niamh couldn't use that.
117	**Researcher**	**Just really agitated?**
118	Informant	Yeah.
119	**Researcher**	**That's really common. What about any advice for other carers. Is there something you know now that you feel had you known earlier would have been beneficial? Is there something you wanted to share with eating and drinking changes or feeding assistance?**
120	Informant	It is very difficult. And my experience is that you always have to live the illness with the person that you are feeding because what you do today mightn't work tomorrow and what you do one day it might just be a subtle difference. Let's say Niamh's

		sister might have visited once a month and she would say to me “I’ll give Niamh her dinner today, you take a break.” But a month on from the previous month something might have changed and she would still be doing what she was doing a month ago but that might not work, and that would frustrate the hell out of Niamh and it didn’t give me a break then because I would have to come back and help and show her. I don’t know how you do that. You can’t really document that, I don’t know how you can manage that progression or those changes, it’s just very, very difficult. A month ago you might be able to fill the spoon three quarters and now you can’t. Or you would have to put the spoon to the front left side of the mouth or right side of the mouth.
121	**Researcher**	**Gosh and by the time you explain that to somebody who is still probably going to get it wrong because they only listened to half or could only remember and now you are thinking “I gotta stay around now anyway to see what is happening.” If it’s not happening everybody gets frustrated because you have gone off for a walk or something, you come back, now the house is in a bit of chaos and now you have to try to feed her again because it didn’t work out. The real small things sound like they can make a massive difference. And they can really impact mood, because if someone has come in to help to free you up so that you can spend a few moments for yourself especially at that time when it’s such a heavy job, things start not working even with the best intention and that is entirely frustrating.**
122	Informant	What is really difficult, if you are feeding someone like that it probably means their voice is gone and it is difficult for them then to tell the person feeding them that they are doing it wrong. They can’t do that.
123	**Researcher**	**You lose all the politeness in speech if you communicate that way. It’s not going to land the way you would like it to land.**
124	Informant	((laughing))
125	**Researcher**	**Have I got that right?**
126	Informant	Yes ((laughing))
127	**Researcher**	**And that’s if the person is willing enough to stay with you in order to communicate it and that they don’t just give up altogether. Because then everybody is annoyed.**
128	Informant	You just have to have the patience and they just have to understand that what worked one day mightn’t work today, and that it changes like that. If you can get a bit of time to yourself you need to get a bit of time and get out. But it can be difficult.
129	**Researcher**	**(Turns off recording unit)**

APPENDIX 'L'

ILLUSTRATION OF CORBIN & STRAUSS (2008) CODING PROCESS

Stage	Definitition	Example
Open	Segments of data are coded with conceptual labels denoting the concepts they represent.	**Transcription:** Anthea **Reference:** Passage 110 **Raw data excerpt:** "Ordinarily I would have went to Mum (care-recipient) for advice but I couldn't because I couldn't burden her with that as well." **Code:** *Protecting the PwMND from burden* **Transcription:** Oliver **Reference:** Passage 58 **Raw data excerpt:** "I would ignore it (messiness of eating) and just dab it (food residue) off (care recipient's chin) with a tissue you know. I wouldn't bring it to her attention." **Coded:** *Protecting the PwMND from embarressment* **Transcription:** Tony **Reference:** Passage 110 **Raw data excerpt:** "The person who has the illness is directing you (to provide high-risk foods). There has been so much taken away that you don't want to take that as well." **Coded:** *Taking direction in the context of feeding, swallowing and mealtime challenges* **Transcription:** Hallie **Reference:** Passage 190 **Raw data excerpt:** "I know my Mam (care-recipient) would feel worse if I was to sit there and not eat. That would upset her more. She wants the family to be as normal as we possibly can." **Coded:** *Balancing needs and agendas in the context of feeding, swallowing and mealtime challenges*
	Concepts (coded with the conceptual label) are grouped into corresponding categories which can be further developed into sub-categories or abstracted into higher categories.	**Category label:** *Protecting the care recipient* Containing **property**: *Protecting care recipient psycho-emotional status* **Category label:** *Watchful shepherding* Containing **property:** *Balance and compromise*
	The range of properties within each category is demarcated.	**Properties of the category:** *Protecting the care recipient:* 1) Physical status 2) Psycho-emotional status 3) Dignity 4) Quality of life

		Properties of the category: *Watchful shepherding* 1) Problem solving 2) Balance and compromise 3) Gatekeeping 4) Communicating strategically 5) Change management 6) Teamwork and leadership
	The dimensional ranges are scrutinised by the researcher to form a *dimensional continuum.*	**Category:** Protecting the care recipient **Property:** (Care recipient) psycho-emotional status **Dimensions:** Shame, embarressment, isolation, fear, frustration **Category:** Wathcful shepherding **Property:** Balance and compromise **Dimensions:** Balancing needs of self with those of care-recipient Balancing needs of care recipient with those of the wider family unit Balancing the needs of care recipient with those of formal care staff Balancing the needs of formal carer staff with the needs of wider family unit members
Axial	Categories are connected through relationships described by the *paradigm model* whereby causal conditions, context, intervening conditions, action/interactional strategies, and consequences are considered for each category.	**Category grouping:** *Protecting the care recipient* & *Watchful shepherding* **Key connection identified:** *Watchful shepherding* is identified as the core process through which the action/interactions of family carers as operationalised as they seek to protect the care-recipient with the onset of feeding, swallowing and mealtime-related challenges associated with MND. Protection is found to extend beyond orientation to the care recipient, towards members of the woder family unit (this orientation and prioritisation occurs based on numerous causal/conditional/intervening factors e.g. care giver, care-recipient, family, and formal care factors as well as the psycho-emotional landscape within which the feeding, swallowing and mealtime impairment is situated)
	Overarching categories emerge.	*Protecting* is identified as the core process explaining the action/interactions of family carers in providing care in the context of feeding, swallowing and mealtime difficulties induced by MND. *Protecting* is designated as the **core category** given the influence of this process on the action/interactions and consequences of family carers providing care in the context of feeding, swallowing and mealtime challenges.
Selective	Categories are integrated with higher levels of abstraction and validated against the data obtained.	**Key conxtextual conditions** influencing orientation of *protecting,* and which underpin the process of *protecting* Bearing, braving and persevering Sadness and loss Guilt and regret Anger and frustration

	Theoretical sampling is used to ensure the data is conceptually dense and sufficiently contextualised.	Fearfulness Hope **Target:** Hope Sampling to understand: ➔ Role of hope in how family carers orientate protection (towards the care recipients vs. self vs. the wider family unit)=role of hope emerging as central/critical to the experience of family carers as they navigate feeding, swallow and mealtime challenges ➔ Impact of hope on *remaining present in the moment (via living in the moment & learning in the moment.* Required due to: *unpredictability, uncertainty, and a lack of control over the progression of feeding, swallowing and mealtime impairment* ➔ Impact of hope on engagement with HSCPs/formal care services ➔ Impact of hope on engagement with strategies to compensate for care recipient feeding, swallowing and mealtime disability

APPENDIX 'M'

CRITERIA FOR EVALUATING THE QUALITY OF GROUNDED THEORY STUDIES (CORBIN & STRAUSS, 2015)

Checkpoints that researchers and reviewers can use to evaluate the methodological consistency of a Grounded Theory study
What was the target sample population? How was the original sample selected?
How did sampling proceed? What kinds of data were collected? Were there multiple sources of data in multiple comparative groups?
Did data collection alternate with analysis?
Were ethical considerations taken into account in both data collection and analysis?
Were the concepts driving data analysis arrived at through analysis or were concepts derived from the literature and established before data was collected?
Was theoretical sampling used, and was there a description of how it proceeded?
Did the researcher demonstrate sensitivity to the participants and to the data?
Is there evidence or examples of memos?
At what point did data collection end or a discussion of saturation end?
Is there a description of how coding proceeded along with examples of theoretical sampling, concepts, categories, and statements of relationship? What were some of the events, incidents, or actions (indicators) that pointed to some of these major categories?
Is there a core category, and is there a description of how that core category was arrived at?
Were there changes in design as the research went on based on findings?
Did the researcher(s) encounter any problems while doing the research? Is there any mention of a negative case, and how was that data handled?
Are methodological decisions made clear so that the readers can judge their appropriateness for gathering data (theoretical sampling) and doing analysis?
Was there feedback on the findings from other professionals and from participants? And were changes made in the theory based on this feedback?
Did the researcher keep a research journal or notebook?

Checkpoints that researchers and reviewers can use to evaluate the quality and applicability of a Grounded Theory study
What is the core category, and how do the major categories relate to it? Is there a diagram depicting these relationships?
Is the core category sufficiently broad so that it can be used to study other populations and similar situations beyond this setting?
Are each of the categories developed in terms of their properties and dimensions so they show depth, breadth and variation?
Is there descriptive data given under each category that brings the theory to life so that it provides understanding and can be used in a variety of situations?
Has the context been identified and integrated into the theory?
Has process been incorporated into the theory in the form of changes in action-interaction in relationship to changes in conditions? Is action-interaction matched to different situations, demonstrating how the theory might vary under different conditions and therefore be applied to different situations?
How is saturation explained, and when and how was it determined that categories were saturated?
Do the findings resonate or fit with the experience of both the professionals for whom the research ended and the participants who took part in the study? Can participants see themselves in the story, even if not every detail applies to them? Does it ring true to them (Lomberg & Kirkevold, 2003)? Do professionals and participants react emotionally as well as professionally to the findings?
Are there gaps, or missing links, in the theory, leaving the reader confused and with a sense that something is missing?
Is there an account of extremes or negative cases?
Is variation built into the theory?
Are the findings presented in a creative and innovative manner? Does the research say something new or put old ideas together in new ways?
Do findings give insight into situations and provide knowledge that can be applied to develop policy, change practice, and add to the knowledge base of the profession?
Do the theoretical findings seem significant, and to what extent?
Do the findings have the potential to become part of the discussions and ideas exchanged among relevant social and professional groups?
Are the limitations of the study clearly spelled out?
Are there suggestions for practice, policy, teaching, and application of the research?

APPENDIX 'N'

ADAPTED INTERVIEW GUIDE

Semi-structured interview schedule: Theoretical sampling guide post interview #15 ("Oliver")

Probes for theoretical sampling

1. I'd like to invite you to talk about your experience of mealtimes since MND came into your life.

2. Can you describe the impact feeding, swallowing and mealtime difficulties has had on you?

3. Many participants in the past have discussed the importance of **protecting dignity** for the PwMND. Is this something you consider when assisting your family member with feeding, swallowing and mealtime challenges?
   -Does this impact your **role** (e.g., engagement with healthcare professionals)?
   -Does this impact how you make **decisions?**

4. Other participants have explained the need to **monitor their own mental health** when providing care for PwMND. Are there specific aspects of care in relation to feeding, swallowing and mealtimes that prove challenging?
   -How do you overcome these challenges?

5. I'm aware that part of your role as a carer involves monitoring for changes and complications around feeding, swallowing and mealtimes. Are there times when you are **reluctant to discuss** changes/observations with the PwMND?
   -Do you always feel you can be open with these observations?
   -Others have mentioned a reluctance to be open at times, are there any circumstances in which you would be reluctant?

6. I understand that changing from **normal behaviour** (e.g., shared meals) to **new normal behaviour (**e.g., separate meals) represent a significant change, can you describe the process this involved for you?
   -How did the change come about?
   -Were you at any time reluctant to change?
   -What was the course/nature of this reluctance?

7. Do you make **compromises** in relation to how you eat/drink?
   -How does this impact you?

8. Has the process of **role change** (e.g., assistance with feeding, swallowing and mealtimes) impacted your **relationship with the care-recipient**? Are there specific challenges around this you have met? What has been helpful?

9. Do you ever feel you **lack control** around feeding, swallowing and mealtime difficulties? Does this have an implication for your mental health? Does this impact the way you view **dignity** for yourself or the care-recipient?

10. One of the main concepts coming through in analysis of the data for this study is **protection.** Does this concept resonate with your experience? Could you describe how so?

In general, are there any **recommendations you could suggest** for other carers of individuals with swallowing impairment due to MND?
-Is there anything that you know now that you **wish you knew at the beginning**?

In general, are there any **recommendations you could suggest for professionals** working with carers of individuals with swallowing impairment due to MND?

Is there anything else that comes to mind, which we have not yet discussed, that you feel is important to help understand what it is like for you to be a carer of a person with feeding, swallowing and mealtime difficulties?

APPENDIX 'O'

DATA DRIVEN ACTION/INTERACTION INFLUENCING CONDITIONS MAPPED USING THE CONDITIONAL/CONSEQUENTIAL MATRIX (CORBIN & STRAUSS, 2008/2015)

	Parameter
Individual level	Age Gender Ethnicity Personality type and temperament Health status (e.g., physical/psycho-emotional) Disability conceptualisation Conceptualisation of caregiver role (specifically in supporting mealtime functioning) Availability of resources to support care (e.g., financial, formal care, family) Life experience (e.g., previous experience with feeding, swallowing and mealtime challenges; previous interfacing with healthcare professionals) Personal value of food, drink and mealtime rituals
Family carer – care recipient relationship	Traditional nature of the relationship (emphasis on power balance) Relationship quality and communication style within the dyad Importance of shared food, drink and mealtime rituals within the dyad
Care recipient level	Age Gender Ethnicity Personality type and temperament Living arrangement Health status (e.g., physical/psycho-emotional) prior to MND diagnosis Status of disease (e.g., type, progression, familial/sporadic nature) Level of feeding and swallowing disability and associated care requirements Co-occurring communication difficulty and communication capacity Life experience (e.g., previous experience with feeding, swallowing and mealtime challenges; previous interfacing with healthcare professionals) Disability conceptualisation Coping and adaptation style (including acceptance of the illness and support)
Family level	Disability conceptualisation Dependency of multiple family members within the family unit Experience with family-based care (including care to support mealtime function) in the family unit Capacity to provide care as a team Traditional role delineation amongst family members in respect to mealtime logistics and illness-associated changes Level of family cohesion, flexibility and ability to adapt to challenges Communication style Role of family-centred food and drink related routines
Community level	Conceptualisation of disability (e.g., inclusivity) Level of community-based support available to optimise care-recipient feeding, swallowing and mealtime function Level of community-based support available to optimise family carer support
Organisational level	*National Health Service* Range in formal care supports available to the care dyad Quality of formal care supports available (e.g., skill set, experience, consistency/flexibility in care, relationship and rapport)

APPENDIX 'P'

SPEECH AND LANGUAGE THERAPY

CLINICAL CONSIDERATIONS ARISING FROM THE DATA

Prior to referral
Examine assumptions and expectations regarding the role of family carers in supporting clinical intervention
Consider theoretical foundations guiding family-centred practice in the context of MND. For example: • Models of palliative care (e.g., Sepúlveda et al., 2002) • Family systems theory (e.g., Bowen, 1978) and models of family systems (Olson, 2000) • Family illness model (e.g., Rolland, 1994) • Coping styles (e.g., Endler & Parker, 1990; Lazarus & Folkman, 1984)
Consider therapeutic qualities conducive of enhanced family carer experiences of care. For example: • Flexibility • Responsiveness • Attentiveness • Trustworthiness • Knowledgeability • Fairness • Comprehensiveness of care
Consider availability of local supports for family carers. For example: • Support groups (e.g., Family Carers Association) • Services available via voluntary bodies (e.g., Irish Motor Neurone Disease Association) • Access to HSE funded supports (e.g., Psychology/Social Work) • Access to generic carer skills training
Referral
Establish the family-based support structures that are in place at the time of referral: • Document contact details for family members involved in supporting home-based care • Seek information regarding primary carer vs. team-based approach currently in place • Seek information regarding family members routinely present during eating/drinking/mealtimes
Establish preferences of primary service users regarding information sharing with family members; obtain consent to share information as appropriate
Initial contact
Discuss SLT role with reference to management of physical, psycho-emotional and psycho-social aspects of feeding, swallowing and mealtime disability
Confirm primary service user consent for SLT care to include family members at risk of third-party feeding, swallowing and mealtime-related disability
Establish primary service user expectations regarding SLT care delivery in the context of a family-orientated approach
Confirm family unit preferences for navigating information sharing and decision-making in the context of feeding, swallowing and mealtime disability
Establish preferences for the location of care delivery (e.g., clinic, remote and/or domiciliary-based) in consideration of the impact on the family unit
Establish preferences for the timing of intervention (e.g., early screening/comprehensive assessment vs. watch and wait protocol) in consideration of the impact on the family unit
Establish primary service user and family carer preferences regarding family carer contribution to informal care (e.g., capacity for early symptom surveillance, logistical management of formal-informal care interface etc.)
Confirm available methods for family members to contact SLT services (e.g., text, email, telephone); emphasise accessibility for all members of family unit (appropriate to primary service user consent)

Ongoing intervention
Ensure SLT assumptions regarding the role of family carers in providing support in the context of feeding, swallowing and mealtime impairment are aligned with family carer capacity and expectations of the family unit regarding the role of family carers
Set goals for dysphagia management collaboratively with members of family unit who support home-based care; review goals frequently and adjust as appropriate to need
Consider the impact of dysphagia recommendations on the dignity, identity, relationships and normalcy of the primary service user as well as on members of the wider family unit: • Ensure recommendations are made based on a comprehensive assessment of potentially variable physiological and environmental factors • Prioritise relationship and identity preserving food and drink-related routines and rituals with **highly individualised** and quality of life focused dysphagia recommendations • Exercise caution regarding preemptive introduction of compensatory strategies to support feeding, swallowing and mealtime function • Provide options and choices for management following a comprehensive determination of risk/benefits to guide dysphagia management decisions
Consider the coping styles of family carers and individualise SLT engagement to align with this status (e.g., consider emphasising practical strategies for individuals tending towards task-orientated coping styles vs. counselling and support for individuals tending towards emotion-orientated coping styles)
Monitor negative psycho-emotional and psycho-social sequelae associated with feeding, swallowing and mealtime impairment experienced by family carers. Conduct targeted clinical interviews (in the absence of formalised screening tools to assess third-party disability in MND-induced dysphagia) to address this area. Consider events aligned with a deterioration in the primary service users dysphagia trajectory (e.g., new requirement for adapted cutlery, food avoidance, withdrawal from social eating, dependency for feeding) as potential influencing conditions on family carer psycho-emotional and psycho-social status
Ensure family carers have direct access to SLT intervention if required to support them in the context of third-party feeding, swallowing and mealtime impairment; especially important within highly sensitive situations such as those involving eating and drinking 'at risk' and gastrostomy decision-making
Consider routine screening of family carer psycho-emotional status at regular time points in clinical interventions. Address dysphagia-specific concerns as appropriate and consider onward referral for additional supports (e.g., Psychology/Social Work) when indicated
Monitor the suitability of agreed service delivery models amongst the members of the family unit and adjust the location, frequency and intensity of SLT intervention as indicated to meet the evolving needs of the family unit
Monitor (potentially changeable) information sharing and decision-making preferences within the family unit. Ensure information shared to support care is available in multiple formats (e.g., verbal, written, online), and is accessible for individuals with all levels of health literacy and for whom English is not their first language
Remain cognisant of potential challenges to the relationship dynamic within the care dyad imposed by SLT intervention (e.g., avoiding reliance on family carers to influence the decision-making of the care-recipient such as in the case of adherence to recommendations); at all times acknowledge the primacy of the traditional relationship between members of the care dyad