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Mutual Support Between Patients and Family Caregivers in Palliative Care

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requirements for the Degree of Doctor of Philosophy

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Declaration

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Rachel McCauley

March 2024

Summary

Background: Palliative care is an interdisciplinary care approach to enhance quality of life and alleviate symptom distress for people living with life-limiting conditions and their families. Support provision between patients and family caregivers in palliative care is often assumed as unidirectional (i.e., from caregiver to patient). A systematic review conducted by the author on mutual support between patients and family caregivers in palliative care showed a dearth of evidence on how the patient and family caregiver reciprocate in the provision of support to one another. This study aimed to identify 1) processes of mutual support between patients and family caregivers in palliative care; 2) factors which facilitate and/or restrict mutual support between them; and 3) how mutual support impacts on how the patient and family caregiver engage in the decision-making process pertaining to care.

Methods: A qualitative study using grounded theory methodology was conducted with 15 patients with advanced illness (cancer n=14, neurodegenerative n=1) and 21 family caregivers (total n=36). Participants were purposively and theoretically sampled from a large regional specialist palliative care service. The participants comprised 14 patient and family caregiver dyads, seven non-dyad family caregiver participants and one non-dyad patient participant. Thirty qualitative interviews in total were conducted with participants using semi-structured interview guides. All interviews were digitally recorded and transcribed verbatim. Interviews were member checked with participants and the data were analysed using grounded theory coding procedures. Memoing assisted the analysis of the data.

Findings: Mutual support comprised two main forms, conceptualised and labelled as direct and indirect. Direct mutual support occurred when patients and family caregivers reciprocated by providing similar types of support to one another and which manifested primarily as various forms of emotional support. Indirect mutual support occurred when patients reciprocated by providing emotional support to the family caregiver in lieu of other supports they were no longer able to provide. Mutually supportive behaviours between patients and family caregivers comprised mutual disclosure, open communication, overt expression of affection and gratitude, remaining positive for one another, seeking to maintain normalcy for one another,

providing counsel to each other, adapting to the challenges of life-limiting illness together, and making decisions about palliative care together. Mutual support was underpinned by mutual concern which could result in mutual concealment of distress and care preferences. Facilitators of mutual support included patients and family caregivers having had a close relationship prior to the patient's illness, patients and family caregivers having trust in one another, patients and family caregivers feeling they had some control and choice in their relationship (which included family caregivers assuming caregiving duties by choice), family caregivers feeling competent in a caregiving role, patients and family caregivers being intuitive about each other's needs, and having support from formal healthcare services and the wider family available to them. Barriers to mutual support included prior conflict between the patient and family caregiver, the absence of wider family support for the family caregiver, conflict within the wider family, and anticipatory grief experienced by both the patient and family caregiver.

Patients reciprocated family caregiver support by involving them in the decision-making process for treatment and care. Family caregivers tended to be heavily involved in decision-making when family caregivers assumed caregiving duties by choice and when the patient did not feel restricted by their reliance on their family caregiver. Family caregivers who felt obliged to care were those who felt they had limited choice in their caregiving role. In some cases, these family caregivers had difficulty communicating with the patient in decision-making. The majority of patients preferred to make decisions with their family caregiver or at least involve their family caregiver directly in discussions about care. Family caregivers themselves were motivated to make decisions with the patient to honour the patient's wishes. Patients and family caregivers collectively engaged in decision-making out of concern for one another and the wider family.

Conclusions: This study found provision of support between patients and family caregivers in palliative care can be bi-directional. Multiple micro (i.e., relationship based) factors impact on the patient and family caregiver capacity to support one another. Mutual support between patients and family caregivers in palliative care functions in the context of both obligation and choice. Patient and family caregiver

perceived obligation to each other can limit disclosure in decision-making. The findings serve to inform the development of psycho-social interventions for patients and family caregivers in palliative care where the focus is on facilitating both the patient and family caregiver in the decision-making process for care. Investigation of mutually supportive behaviours between patients and family caregivers beyond cancer in palliative care is warranted to substantiate the study findings.

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Chapter 1: Introduction and Literature Review

Chapter 1: Introduction and literature review

1.1 Introduction

Palliative care is defined as an interdisciplinary care approach to enhance quality of life and alleviate symptom distress for people living with life-limiting conditions and their families, and especially of those at the end of life (Radbruch et al., 2020). In palliative care, family caregivers can provide a significant amount of informal caregiving to the ill person they care for (Hudson & Payne, 2011), comprising a combination of physical, psychological, social, and existential support (Alam et al., 2020; Ateş et al., 2018).

Caregiving extends from the provision of physical and emotional care to advocating for patient services and coordinating care for the patient, particularly when services are received by patients in the home setting (Morris et al., 2015). As the delivery of palliative care services moves increasingly toward community-based care, it is expected that family caregivers will continue to be heavily involved in the delivery of palliative care (Murray et al., 2015). Considering the complexity of the conditions of patients receiving palliative care, the above undertaking is not adopted lightly, with family members spending large proportions of their time and their physical and emotional energy on caregiving tasks (Reigada et al., 2015). That said, and notwithstanding the pivotal role of the family caregiver in palliative care, there has been less focus in palliative care on how patients function as providers of support to their family caregiver (Foley, 2018), and how the patient and family caregiver can be mutually supportive to each other (McCauley et al., 2021).

1.2 Background and rationale for the study

The family caregiver in palliative care is an individual who leads a dual role, both as part of the unit of care and as part of the caregiving team. However, research in the field of life-limiting illness also reports on patients' wishes and perceived ability to provide support to their family caregiver and reciprocate in the provision of support between them and their family caregiver (Cilluffo et al., 2021; Proot et al., 2004; Traa et al., 2015). There is evidence that the provision of psychological and emotional support from the person with a life-limiting illness to their family caregiver not only

assists the family caregiver cope with the demands of caregiving, but also enables the patient and family caregiver adjust collectively to the challenges of living with life-limiting illness (Gardner, 2008). Support between patients and family caregivers in palliative care can be bi-directional and people with life-limiting illness have reported directly on their own ability to provide support and care to their family caregiver (Hauser et al., 2006). However, little was known about key processes of mutual support between patients and family caregivers in palliative care and in what contexts such mutual support manifests and functions. Moreover, the impact of patient and family caregiver reciprocal support in palliative care on the decision-making process for treatment and care was unclear. Family caregivers in palliative care are invariably key stakeholders in the decision-making process for care (Le Blanc et al., 2022). We know that patients and family caregivers can accommodate each other's preference for care (Mulcahy Symmons et al., 2023) and that patients' and family caregivers' sense of responsibility to one another prompts both to make decisions about care to protect one another (Foley & Hynes, 2018). A fuller understanding of the bidirectional nature of support provision between the patient and family caregiver in palliative care necessitates further research into the supportive roles and behaviours that constitute and explain how patients and family caregivers can be mutually supportive, including how their reciprocity impacts on both their preferences for and choices about care.

1.3 Aims, research questions, and scope of the study

The study aims were three-fold. For the purposes of clarity within the aims, the term 'action' is given the operational definition of a purposeful, conscious act. The term 'behaviour', alternatively, is defined as the often-subconscious attitude conveyed by an individual while carrying out an act.

The study aimed to:

1. Identify and explain key processes of mutual support between patients and their family caregivers. Here, the study sought to identify and explain behaviours, actions, and interactions between patients and family caregivers in palliative care that comprise mutual support between them.

2. Ascertain what contexts (i.e. factors) can facilitate and/or restrict mutual support between patients and family caregiver in palliative care.
3. Identify and explain how mutual support between patients and family caregivers in palliative care impacts on how both the patient and family caregiver approach and/or engage in the decision-making process pertaining to care.

Given the aims of the study as stated above, the research questions were the following:

1. What are key processes of mutual support between patients and family caregivers in palliative care?
2. What factors facilitate and/or inhibit mutual support between patients and family caregivers in palliative care?
3. How does mutual support between patients and family caregivers in palliative care impact on their decision-making pertaining to care?

The research questions are context driven because it is assumed that multiple contextual factors (both micro and macro) can shape patient and family caregiver relationships in palliative care, and which are 'grounded' in the everyday experience of both patients and family caregivers. Contextual factors can vary between patients and family caregivers in palliative care, but they also converge at some point to explain (in the case of the present study) mutual support between patients and family caregivers. In terms of the scope of the thesis, the findings allow for comparison across similar and different contexts in palliative care. In other words, the findings are of relevance for palliative care beyond merely the settings used for recruitment in the study and yield important insights that are applicable across patient and family caregiver relationships in life-limiting illness.

1.4 Definition of key terms

Palliative care: Palliative care is defined as an interdisciplinary care approach to enhance quality of life and alleviate symptom distress for people living with life-limiting

conditions and their families (Radbruch et al., 2020). It is understood as the active and holistic care of people with serious health-related suffering due to severe illness, and especially of those nearing the end of their lives (Radbruch et al., 2020). As outlined in chapter three, participants of the study were recruited from two hospice sites which constitute a large regional specialist palliative care service in the Republic of Ireland covering an area of ca. 700,000 people. Palliative care was provided to participants at these sites in line with the above definition.

Patient: The term 'patient' in the study refers to a person living with a life-limiting illness and in receipt of palliative care from formal healthcare services. The term life-limiting illness is understood as an incurable condition that would shorten a person's life.

Family caregiver: The term 'family caregiver' is defined as any relative, partner, or friend who has a significant relationship with and provides care to the person (i.e., patient) they care for. As described in chapter three, family caregivers recruited in this study were identified by the patient in receipt of palliative care as their primary family caregiver.

Informal care: Informal care is defined in the present study as care provided by family caregivers, as defined above, of the patient. The author wishes to acknowledge that her use of the term 'informal care' seeks only to delineate those related to the patient through informal channels such as family or friends, from those who care for the patient in a professional capacity, and not to undermine the high value of non-professional caregiving.

1.5 The researcher's context

Reflexivity is a term that refers to the researcher's awareness and acknowledgement of their own influence (and potential biases) on the research undertaken by them (Hall & Callery, 2001). Making known the position of the researcher is important contextual information for the transparency of a qualitative study. Qualitative researchers need to be aware of how their own perceptions and biases impact on the data generated in the study (Denzin & Lincoln, 2018). The author had already undertaken research as a

research assistant in palliative care and had accumulated knowledge pertaining to availability of palliative care services, both nationally and internationally (Johnston et al., 2020). In addition, she had previously undertaken qualitative research with gay and bisexual men in Ireland regarding factors which inhibited the uptake of HIV rapid testing, many of whom were bereaved partners and friends of people who had HIV. As such, the author felt she has a solid grasp of the sensitivities required to undertake the project described in this thesis. Overall, the author sought to remain fully sensitive to participants' perspective. She sought to be continuously alert to the viewpoint of participants and to how her own knowledge and context as a researcher could impact on the conduct of the study.

1.6 The context of palliative care services and research in Ireland

The study was conducted in Ireland where palliative care provision is thought to be of high quality when compared to international standards. For example, a report by the Economics Intelligent Unit in 2015 (Economist Intelligence Unit, 2015) ranked Ireland fourth among a total of 80 countries in terms of palliative care provision, and a cross country comparison of expert assessments of the quality of death and dying in 2021, ranked Ireland second among 81 countries in terms of quality of death and dying (Finkelstein et al., 2022). Furthermore, the quality and impact of research conducted on the island of Ireland continues to increase and is attributed to increased collaborative networks both nationally and internationally (McIlfatrick et al., 2018). However, research gaps remained including studies focused on the patient and family caregiver perspective (McIlfatrick et al., 2018). The author found only a limited number of palliative care studies which had investigated any aspect of mutual support between patients and family caregivers in palliative care (McCauley et al., 2021), and no study had set out to investigate reciprocity in the provision of support between patients and family caregivers in palliative care in an Irish context. Hence, the study outlined and reported in this thesis is the first of its kind to be conducted in Ireland.

It is important to note the study reported in this thesis was heavily shaped by COVID-19, a period in which palliative care was testing to deliver (Janssen, 2021) and palliative care research involving patient and family caregiver involvement was challenging to

undertake (Walshe, 2021). Data collection occurred either in periods of national ‘lockdown’ or thereafter during periods in which those who were medically vulnerable continued to necessitate a high level of vigilance (Hartigan et al., 2021). In the case of community-based care, apart from direct contact with formal healthcare services, patients receiving palliative care and their family caregivers in Ireland were subject to long periods in which they spent time together. Conversely, they were subject to periods of separation in the case of inpatient care. The findings reported in chapters four, five, and six of the thesis are contextualised not only to palliative care provision in Ireland, but also to the impact that COVID-19 had on palliative care services in Ireland.

1.7 Literature review

With the aims of the research sufficiently understood, a review of the research is necessary to ascertain what is known about the topic of mutual support. This necessitates an understanding of what comprises palliative care and the contexts in and from which palliative care operates for patients and family caregivers. Sections 1.7.1 to describe the extensive review of literature pertaining to the topic of mutual support. The role of the family caregiver and dimensions to patient and family caregiver relationships in palliative care are described in detail. Patient and family caregiver mutuality is outlined in the context of how the patient and family caregiver adapt to life-limiting which includes how they impact emotionally on one another. Motivation in caregiving for family caregivers is explored through theory and evidence pertaining to obligation and choice.

1.7.1 Living longer in Ireland with life-limiting illness

Ireland has the highest life expectancy at birth of the EU-27 countries with Irish women predicted to live to 84 years and men to 81 years on average (Organisation for Economic Co-operation and Development, 2022). This increasing life expectancy is in part a result of the care received by individuals with life-limiting illness, including having access to and using healthcare services (Sinnott et al., 2017). Irish governmental schemes such as the Long-Term Illness scheme (which provides approved medicines and appliances to people with some long-term and/or chronic illnesses irrespective of

income) and the General Medical Services scheme (which provides free access to available healthcare below income threshold), have resulted in more widespread access to medication and treatment (Barry & Tilson, 2007; Hernández et al., 2021). This has resulted in a large majority of Irish adults having access to treatment and medications which prevent, cure, or decelerate disease progression, and in turn reducing mortality from Ireland's leading causes of death; diseases of the circulatory and respiratory systems diseases, and cancer (Ward et al., 2020). Notably, cancer survivorship, defined as five-year survival after diagnosis, has increased by 50% in Ireland in the last ten years, illustrating an increase in early diagnosis and effective treatment for people with cancer (National Cancer Registry Ireland, 2022). Five-year survival post-diagnosis in cancer has risen to 65% in Ireland as of 2022, a marked difference from those diagnosed with cancer between 1994-1998 who had a 45% likelihood of five-year survival (National Cancer Registry Ireland, 2022)

1.7.2 The increasing need for palliative care

Novel treatments are leading to extended life expectancies across the developed world. As a result, many people are living for much longer and developing co-morbidities with which they can live with and manage, and so increasing their life expectancy. However, this has also increased the need for healthcare services to attend to the expanding number of people requiring palliative care (Etkind et al., 2017). While there has been an increased quantity of life observed in the developed world, recent evidence has also highlighted the lack of proportionate increase in the quality of life experienced by older people within their additional years of life (Brown, 2015). With increased life expectancy, a more significant proportion of the population are affected by age-related diseases such as cancer, respiratory disease, cardiovascular disease, arthritis, dementia, and other neurodegenerative conditions (Brown, 2015; Z. Li et al., 2021). Consequently, palliative care is a rapidly evolving area of healthcare provision in the context that people are living longer with life-limiting conditions and receive palliative care before the end-of-life period of their illness (Vogt et al., 2021).

1.7.3 The development of the palliative care approach

While palliative care is often understood to differ from traditional curative medicine in terms of its treatment of physical pain and symptoms, namely its focus on comfort over cure, it also differs with respect to its philosophical origins and aims. Palliative care includes focus on alleviating ‘total pain’, which is defined as all forms of pain including psychological, spiritual, and social (Saunders, 1964; 2001). The focus on ‘total pain’, a term coined in 1964 by the founder of the modern hospice movement, Cicely Saunders (Saunders, 1964) is where palliative care deviates from traditional medicine, focusing on holistic treatment that requires a multidisciplinary team. The palliative care team includes a broad range of healthcare professionals including for example, medical doctors, nurse specialists, occupational therapists, physiotherapists, social workers, dietitian and nutritionists, psychologists, and counsellors. Since the 1960s, palliative care has evolved further whereby specialist multidisciplinary teams in palliative care now provide palliative care to patients and their families with or without aggressive treatments which attempt to lengthen life. Importantly, palliative care can also act complementarily to curative treatments, with evidence indicating that the care received by patients from oncology care teams can be ameliorated by early intervention from palliative care (Pirl et al., 2012).

The definition of palliative care has further broadened in the last decade, with the 67th World Health Assembly of 2014 deeming that healthcare professionals have an ethical obligation to alleviate suffering regardless of the degree of curability of a patient’s illness (World Health Organisation, 2014). Contemporary palliative care has now evolved to an approach which aims to enhance quality of life of patients navigating the physical and psychological effects of life-limiting illness at any stage of their illness, through the provision of physical, psychosocial, and spiritual support.

1.7.4 Palliative care and end of life

Palliative care, unlike emergency treatment, attempts to ensure that patients experience death as they wish to by both planning for a comfortable death, while also developing and implementing plans which will ensure the death of a patient takes

place in their intended setting. The idea of a 'good death' is a key tenet of palliative care. The goal of palliative care is therefore to alleviate suffering and improve quality of life for patients and their families, and to anticipate and plan for comfortable and peaceful death for the patient (Mercadante et al., 2018). This sets palliative care apart from other forms of medical treatment of illness, the main goal of which is to prevent death rather than to accept its inevitability and anticipate its imminence (Mercadante, 2023; Waterer et al., 2018). Despite traditional assumptions about palliative care, palliative care can be introduced at any stage of illness, both running parallel to or in lieu of curative treatments where palliative treatments intensify towards the end of life (Cook & Rocker, 2014; Schlick & Bentrem, 2019). Recent estimates regarding the future need for palliative care predict that due to increased life expectancy of populations, the number of people that will require palliative care to manage and treat morbidity at the end of life will have doubled by 2040 (Etkind et al., 2017). This is in part a consequence of better resources with which to detect cancer and other conditions and administer preventative and curative treatments, resulting in fewer cases of sudden death than in previous decades (Howie & Peppercorn, 2013). Patients' symptoms are being managed in a more successful and life lengthening way, as the transition to palliative care opens opportunities for patients and their families to implement more carefully discussed and organised end of life plans, which may ultimately lead to care that meets a patient's wishes (Brinkman-Stoppelenburg et al., 2014).

As outlined, the contemporary definition of palliative care is an approach of which the central aims are to alleviate suffering and improve the quality of life of patients and their families, and to apply a more holistic approach to healthcare than standard curative treatment alone (Khan et al., 2014). Pain and symptom management, management of curative treatments in conjunction with early stages of palliative care, psychosocial and spiritual care for patients, anticipatory grief and post-bereavement care for families, and emotional support for the family-patient unit collectively comprise a palliative care approach (Connolly & Charnley, 2015). It is considered important that patients have access to palliative care to experience the benefits of palliative care and to have their wishes for their end-of-life care met.

1.7.5 The effects of palliative care interventions on patients receiving palliative care

Research has illustrated a range of benefits for patients receiving palliative care (Higginson & Evans, 2010). Such benefits include a decrease in overall symptom intensity (Bakitas et al., 2009), depressive emotional state (Bakitas et al., 2009; Nieder & Norum, 2012), anxiety (Nieder & Norum, 2012), pain severity (Strömngren et al., 2004), and nausea and vomiting (Mercadante et al., 2000), in addition to a decrease in number of hospital admissions (Spilsbury et al., 2017). Further to the aforementioned benefits, evidence also shows an increased self-reported quality of life in patients (Kamal et al., 2013), improvement in patients' mood (Temel et al., 2017), and an increase in patients' utilisation of coping strategies (Jacobs et al., 2017a). Patients have also been found to be impacted by the timing at which palliative care is introduced in the course of their treatment. Early introduction of palliative care has been found to reduce patient anxiety, increase patient satisfaction, improve quality of life, and reduce pain in patients whether at home, in hospice, or in inpatient settings (Higginson & Evans, 2010). These benefits were enhanced when a patient's wishes for their end-of-life are met and with over 70% of patients wishing to spend their palliative period at home, additional resources are required to best support patients in the home (i.e., community-based) setting (McKeown, 2014).

1.7.6 Preferred place of death for patients in palliative care

Across the world, the large majority of patients' preference for place of death is their own home (Gomes et al., 2012; Foreman et al., 2006; Higginson & Sen-Gupta, 2000). In Ireland, over 70% of Irish people voice their wish to die at home. However, in actual terms, deaths at home represent only 23% of deaths in Ireland, with 44% of patients dying in hospital and the remainder dying in hospice, nursing homes, and other inpatient settings (Matthews et al., 2021). This percentage reduces to 17% in Dublin with the lack of capacity in home care and reliance on hospital services when compared to outside Dublin (Matthews et al., 2021).

While patients attempt to cope with the loss of control that accompanies the illness trajectory, the ability to regain some control in selecting their preferred place of death

is important to them and is also considered a key indicator for ameliorating the quality of their end-of-life (Ali et al., 2019). Allowing patients to access palliative care in their preferred setting is central to reaping the benefits of palliative care. Their preference, which is skewed in favour of dying at home, generally remains consistent throughout the illness trajectory (Gomes et al., 2013). Consequently, a large proportion of care is classed as ‘informal’ⁱ and is provided by family and/or friends of a patient, depending on the availability and capability of such individuals to provide care (Knighting et al., 2015; McKeown, 2014). The attainment of patients’ preferred place of death and the successful continuity of delivery of palliative care can therefore be heavily reliant on assistance from informal sources of support such as family members (Broom & Kirby, 2013). Both patients and family caregivers tend to require the assistance of palliative care services that provide both physical support to patients and family caregivers at home in addition to assisting patients and family caregivers fully understand the nature of the patient’s illness and give a realistic indication of the patient’s prognosis (Dittborn et al., 2021; Gonella et al., 2021). In the context of patients’ preferences to die at home and inability of healthcare resources to keep pace with our ageing population and ability to providing extended periods of inpatient care for people with life-limiting conditions, palliative care delivery in the community setting is a key feature of palliative care provision in Ireland (McKeown, 2014).

1.7.7 The movement of palliative care to community-based settings

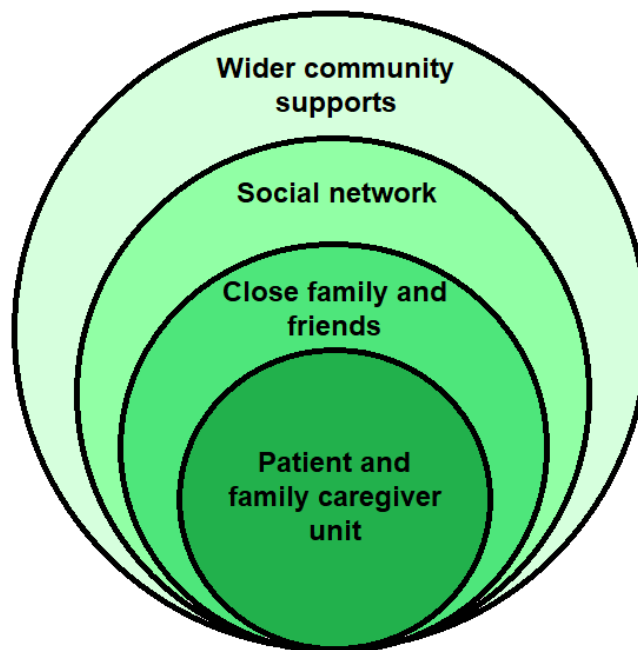
The delivery of palliative care is moving to a more community focused delivery model of care (Gomes et al., 2013). While the introduction of palliative care into hospitals has improved outcomes and life satisfaction in patients and their families, death can still be over-medicalised in these settings (Mouhaweij et al., 2017; Shippee et al., 2018) and lack the resources to provide specialist palliative care involving social and psychological supports in some cases (Hawley, 2017). In addition, a lack of robust recording of palliative care use within hospital settings may result in advanced care plans of patients being neglected within these settings (Matthews et al., 2021). Due to the perceived constraints on hospital staff in providing social and psychological care and the inability of patients and families to access home comforts, many patients are averse to

potentially dying in hospital (Binda et al., 2021). However, these factors are not the only barriers to inpatient palliative care. For example, in Ireland, an estimated 2,500 people are unable to access inpatient specialist palliative care each year (Murray, 2013).

Community-based care allows for more continuous care of the patient in palliative care. Patients can remain in one setting while they advance through different stages of palliative care, transition through different stages of illness and move from a more curative to palliative treatment. Patients' wishes are dependent on those who are available to provide care. In Ireland, informal care makes up 37% of care received by patients at the end-of-life, averaged over all settings, with an inflated percentage in rural areas with lack of access to formal support (May et al., 2020). Both patients and family caregivers in rural settings therefore require more significant contribution from their larger support network. Figure 1 below (pg. 14) illustrates the support network for the patient and family caregiver unit in palliative care.

Community-based palliative care in Ireland is typically a consultant-led service, with some areas of Ireland relying on nurses to lead services due to a lack of access to consultants and healthcare professionals from other disciplines (McIlpatrick et al., 2018). As such, more rural areas of Ireland do not experience the full complement of multidisciplinary services that urban patients and family caregivers benefit from (McIlpatrick et al., 2018). In these cases, due to services lacking in capacity to meet the needs of all patients, both services and patients rely more heavily upon family caregivers to fill the gaps in services to avoid inpatient admissions (May et al., 2020). As such, for the majority of patients' wishes to spend their end-of-life period at home to be realised, family caregivers need to be readily available and equipped with the skills required to provide care (Kristanti et al., 2017; Wu et al., 2020). While often aided by voluntary services and SPC access by phone, family caregivers often have to self-educate in order to meet the needs of the patient that has expressed the wish to remain at home while receiving palliative care. Family caregivers therefore require more formal support and more training in areas with lack of proximity to more central-based palliative care services (Weafer & Toft, 2017).

Figure 1. *Support network for patient and family caregiver unit*



1.7.8 The role of the family caregiver in palliative care

Family caregiving is defined as the collection of processes by which the families and friends of people with needs relating to illness provide informal care. The definition of a family caregiver is a person with a significant relationship with a patient, including family members and friends, that gives voluntary and unpaid care to the patient (Payne, 2010). The question of who becomes the primary family caregiver to the patient is dependent on multiple factors including pre-morbid relationships, norms and traditions within the cultural milieu of the patient, the gender roles within this culture and within the family, and practical issues such as proximity of certain family members to the patient, and the availability of these family members to provide care (Spatuzzi et al., 2022). Indeed, gender norms are still a prevalent factor of family caregiving, whereby in the absence of a spousal caregiver, family caregivers tend to be women more so than men (Ferrell & Kravitz, 2017).

Family caregivers spend a significant proportion of their time providing care to patients and assume family caregiving roles at great detriment to their own needs. While the

average working week is 40 hours, family caregivers can spend up to 70 hours per week on informal caregiving duties (Rowland et al., 2017), leaving little time remaining for self-care acts and socialisation. As a result, family caregivers often find themselves unprepared for the isolation and strain that frequently accompanies the assumption of their new roles. The acknowledgement of the family member or members closest to the patient as a hidden patient is pivotal to the effectiveness of home-based care (Florea et al., 2020), with family caregivers experiencing deterioration of their own physical mental health due to the arduous demands and stressors associated with caring for their ill family member (Ateş et al., 2018; Kristjanson & Aoun, 2004). Family caregivers are central to patients' care, with palliative care professionals considering and treating them as part of the 'unit' of care (Sherman, 2019), with the understanding that their wellbeing can also influence the wellbeing of the patient (Kershaw et al., 2015).

In addition to providing various types of physical and emotional support to patients, family caregivers also assist in advanced care planning and decision-making in relation to care and treatment (Ng et al., 2013; Veloso & Tripodoro, 2016; Yoo et al., 2020). The influence of family members on patient decisions in addition to patient wellbeing cannot be underestimated in terms of its validating and comforting effects on patients (Ragan et al., 2008). Many family members act as a fundamental part of the decision-making unit when making decisions affecting patients' treatments and wishes for care (Dionne-Odom et al., 2019; Ng et al., 2013; Veloso & Tripodoro, 2016; Yoo et al., 2020).

1.7.9 The emotional influence of patients and family caregivers on one another in life-limiting illness

Patients and family caregivers can experience life-limiting illness differently. While patients attempt to come to terms with their imminent death, their often-acute physical symptoms and pain, and their loss of identity and previous roles, family caregivers face challenges such as attempting to plan for the future without the patient, attempting to assist with the patient's pain management, and the loss of their previous lifestyle and self-care behaviours (Mosher et al., 2013). However, patient and family caregiver distress is interdependent and influenced by the emotional state of

their counterpart (Hagedoorn et al., 2008). Patient and family caregiver interdependence for coping in life-limiting illness has been observed in a myriad of studies, highlighting the mutual decline in physical and emotional health, wherein a decline in the emotional or physical health of a patient can trigger an emotional and physical decline in the health of the family caregiver (Sannes et al., 2019; Zwahlen et al., 2010). Patients may also experience adverse health effects as a result of deterioration in the health of their family caregiver.

Harmony or, in some cases, discordance between patients with life-limiting illness and their family caregivers are dependent on factors such as pre-existing conflict (Broom & Kirby, 2013), differing views towards certain topics, changes in identities, the engagement in or avoidance of conflict (Bevan et al., 2012), and resistance in the acceptance of new and difficult circumstances (Carolan et al., 2015). Relationships between patients and family caregivers retain these elements, and are affected by the same influences, while being impacted by the new factors such as the transition to palliative care and the attempt to confront the inevitability of the death of the patient. Such factors can strain even strong pre-morbid relationships and lead to greater anxiety, more depressive symptoms, perceptions of burdening or being burdened, and impairing coping skills among patients and family caregivers (Ferrell & Kravitz, 2017; Wittenberg-Lyles et al., 2019). In relationships with pre-existing conflict, this conflict can carry through to the patient and family caregiver relationships in the post-diagnostic period and may exacerbate as a result of their shared and heightened distress (Broom & Kirby, 2013). As within their pre-morbid relationships, when two individuals, in this case a patient and their family caregiver hold different communication styles, the ability to cope with difficult circumstances can also be impaired (Wittenberg-Lyles et al., 2019; Wittenberg-Lyles et al., 2012). In cases where a discordance in communication styles existed between the patient and family caregiver before the patient's diagnosis such discordance can grow because of the strain of navigating palliative care with one another. Importantly, mutual strain between patients and family caregivers can impede their ability to support and rely on each other (Wittenberg-Lyles et al., 2019).

1.7.10 The patient and family unit in palliative care

As individuals, family members hold expectations upon one another to reciprocate behaviours and emotional responses that each individual displays. This pattern of behaviour and expectation is explained by interpersonal theory, which states that 'within any interaction between two or more individuals, the interpersonal behaviour of each is simultaneously both a cause and an effect of the behaviour of the other' (Wagner et al., 1995, p. 938) In accordance with this theory, patients in palliative care, the central individual in a diagnosis of a life-limiting illness, can influence the behaviours of their family caregivers and indeed, their wider family.

In palliative care, it is within the interests of the patients and their family members therefore that they attempt to co-construct a shared viewpoint with which to react to and interact with one another to adapt collectively to their changing circumstances (Mulcahy Symmons et al., 2023). The response of the wider family to the diagnosis of a patient is pivotal to the success of informal palliative care provision, with each family members' degree of support altering the experience for the patient and indeed the primary family caregiver. Family support can be of vital importance to the wellbeing of both the patient and the family caregiver because of the need for the patient and primary family caregiver to have respite from one another (Jack et al., 2016). Indeed, holding a shared perspective within the family can be pivotal to the avoidance of significant conflict for patient end-of-life care, particularly with regards to decision-making processes for treatment and care (Mulcahy Symmons et al., 2023).

Evidence suggests that relationships between patients and their family members retain elements of their pre-morbid relationships (Meyer et al., 2022). In this way, families in conflict typically remain in conflict after a diagnosis of a life-limiting condition, and harmonious families can remain free from disagreement post-diagnosis, even in the face of their newly acquired distressing circumstances (Broom & Kirby, 2013). This familial cohesion is positively correlated with the ability of patients to find meaning in their end-of-life period (Liu et al., 2022). Due to the influence of familial relationships on patient wellbeing, examination of these relationships is therefore a cornerstone of previously published palliative care research. While palliative care

research focuses on the treatment of the patient and family as a unit of care, few studies view this family as a functioning system in which all parts have a complex and influential relationship with all other family members (Kolmer et al., 2008). Each family member is a significant constituent in the lives of one another with each member influencing the ways in which each other respond and react within the family dynamic. Indeed, the loss of a family member can cause other family members to lose their sense of identity in terms of losing how they related to their deceased relative (Totman et al., 2015).

Expectation of change in roles and identities can greatly impact family members' response to the diagnosis of their family member. Changes in identity and roles most often affect the patient and their primary family caregiver which provides context to family members' careful consideration of who will become the primary family caregiver. Caregiver identity theory suggests that caregiving roles are not a change in role, but rather a transformation of an original role into a care role by acquiring new skills, responsibilities, and concerns over time (Montgomery & Kosloski, 2009). While this is true of spousal caregivers who may have anticipated that they would take up a caregiving role for their spouse over their life course (Kusi et al., 2020), assumption of primary family caregiving responsibility to an ill family member is not necessarily a straightforward process. When the person with the life-limiting illness reaches a point where extensive informal care is required, families are tasked with deciding who will provide the majority of informal care needed by the patient. Some family members feel they are called to care (Haan et al., 2021) while others may feel forced into their new roles (Dittborn et al., 2021). Sections 1.7.11 and 1.7.11.1 next detail theory pertaining to the motivations behind the uptake of the primary family caregiving role, and the differing effects of obligation and personal responsibility of family caregiving on both patients and family caregivers.

1.7.11 Motivations behind family caregiving

As mentioned, family members are encouraged (and relied upon) by healthcare services to supplement care provided by formal services. Family members often act as advocates for patients, partake in decision-making for care and provide emotional

support to the patient. Filial piety is a social construct stemming from patriarchal and traditional cultures where one's parents are held in high regard, respected, and obeyed (W. Li et al., 2021). The concept of filial piety has been considered within the dynamic of patients receiving informal care from their adult children (Lin et al., 2019). This Confucian concept, while derived from Chinese culture, has been found to be present in many cultures particularly with regards to the treatment given by adult-children to their dying parents (W. Li et al., 2021). Irish culture, while different to Chinese culture, holds some similar values, particularly with respect to community and family. Filial piety can be underpinned by self-motivation to reciprocate historical care received from parents. This form of self-directed filial piety is referred to as 'reciprocal filial piety' and defined by W. Li et al. (2021, p.1) as 'sincere affection toward one's parent and a longstanding positive parent-child relationship'. This differs from what is referred to as 'authoritarian filial piety', the traditional form of filial piety which is motivated by obedience to both social obligations and to parents themselves, with little consideration for one's own needs. Overall, filial piety may still play a role in Irish culture (Schwartz et al., 2010), particularly when combined with long-held approaches and traditional views to death, dying, and grieving in Ireland.

1.7.11.1 Obligation and choice

As explained, filial piety and outside social influences can affect an individual's motivation to readily assume the role of primary family caregiver. However, not all individuals who feel obliged to take up caregiving roles do so. Family caregivers can also be indifferent to social norms and not experience the impetus to provide care that often arises from a feeling of obligation. The term 'obligation' may be a more appropriate label for those who do not volunteer readily for caregiving roles but perceive themselves to be forced into or understand themselves to be the only suitable candidate for the role and therefore obliged to provide care (Ng et al., 2016).

However, family members who assume caregiving roles due to perceived historical care debts to their parents or perhaps who wish to share all remaining time with their ill family member, may fall under a different category which includes those under (the aforementioned) 'reciprocal filial piety'. Family caregivers in this category can be

viewed as motivated by ‘personal responsibility’, acting out of internal affection, a sincere desire to take up their role, and the inability to conceive themselves as peripheral to the patient’s end-of-life (Kolmer et al., 2008). The approaches that the two categories of family caregiver as mentioned above (i.e., those who may feel obligated to care and those who act out of their own desire and self-need to provide care) take to their role as caregiver are different in both the day-to-day aspects of the role, the types of communication these family caregivers have with their patients, and the long-term goals and aims of the patient’s care (Kolmer et al., 2008). Family caregivers under the ‘obligation’ category of caregiving, in particular those under ‘authoritarian filial piety’ have found to be averse to becoming a central decision maker in their patient’s care (Dzeng et al., 2022). Conversely, those who are motivated more so by ‘personal responsibility’ can be more actively involved in and more emotionally affected by the decision-making process for patient care (Van Oosterhout et al., 2021).

1.7.12 Patient and family caregiver mutual adaptation in life-limiting illness

The concept of mutuality between patients with life-limiting illness and other family members is often reported in work that covers adaptation to illness. For instance, earlier work by Kissane et al. (1994) on psychological morbidity in the families of patients with cancer recommended that assistance be provided to the family unit as a group, and that processes which optimised trust, communication and shared problem solving within the family should be promoted. The foundations of Kissane et al.’s study is based on earlier research on grieving families following the bereavement of a family member by Williams & Polak (1979). However, Kissane et al. (1994) explored the patient within the family shared coping and in the context of their collective adjustment to the illness and the anticipatory grief that followed the patient’s diagnosis.

It is understood that patients and family caregivers in life-limiting illness constitute an interdependent relational system (Lo et al., 2013). Here, experiences of patients and family caregivers are best understood within the context they share with their counterpart and the interaction of their psychosocial characteristics and the wellbeing

of one another (Lo et al., 2013). However, evidence is limited pertaining to the processes that best describe these experiences, specifically the contexts which underpin success in shared adaption and shared amelioration of their emotional trajectory, and the contexts which underpin maladaptation, conflict, and disruption between the patient and family caregiver.

Research on the relational connectedness of the patient and family caregiver in life-limiting illness would indicate that the pre-morbid relationships between the patient and family caregiver are predictive of the quality and trajectories of these relationships following the patient diagnosis (Johnson et al., 2021; Morrison et al., 2020). In effect, research indicates that quality of relationships can remain 'stable' directly after a traumatic event which suggests that the quality of the relationship between the patient and family caregiver is shaped by their adaptation to the life change caused by the event (Lance et al., 2021). Some existing research indicates that shared adaptation is solely reliant on the quality of pre-morbid relationships without examining further contextual variables (Winter et al., 2011). However, while pre-morbid patient and family caregiver conflict increases the likelihood of patient and family caregiver mutual conflict after the patient's diagnosis, evidence also illustrates that the palliative care experience in of itself can have both positive or negative effects on the patient and family caregiver relationship (Juarez, 2014).

As stated by Meyler et al. (2007) in their systematic review investigating concordance within couples navigating health-related decisions, the mechanisms that lead to concordance between patient and family member are unknown, specifically with respect to what processes, actions and interactions patients and family caregivers influence one another. Studies which have identified the close relatedness of the psychological states of patients and their family caregivers have suggested that healthcare services that can move from patient-focused models of care to models of care that focus on the relationship between the patient and family members have the potential to benefit for both the patient and family caregiver (Knowlton et al., 2021; Mosher et al., 2017; Streck et al., 2020). The above findings are particularly pertinent as we know that mutual understanding between the patient and family caregiver has beneficial effects on patient and family caregiver shared psychological wellbeing

including contributing to a shared sense of control, reducing their shared distress, and improving their collective adaptation and anticipatory planning (Carrillo et al., 2018). Hence, treating the relationship between patients and family caregivers as one in which the patient and family caregiver experience a shared state of wellbeing can provide the basis for shared adjustment in the context of the challenges associated with life-limiting illness and palliative care (Fletcher et al., 2012).

Patients and family caregivers are also strongly influenced by the encouragement or discouragement of one another when patients are facing a life-limiting diagnosis (Lo et al., 2013). Patient and family caregiver encouragement of one another can lead to increased self-efficacy for both within their respective roles. Self-efficacy refers to the degree to which patients and family caregivers evaluate their own abilities (Bandura et al., 1997) and perceive their own mental readiness and capability to cope with and navigate the palliative trajectory. In short, self-efficacy is measured by how able individuals feel they are to fulfil their role as patients or family caregivers (Bandura et al., 1997; Mystakidou et al., 2013). The knowledge that they are perceived to be a 'good' family caregiver can predict family caregivers' caregiving behaviours (Hall, 2014), increase their sense of control over their circumstances (Au et al., 2010), and decrease the strain and anxiety of the family caregiver (Campbell et al., 2004). Self-efficacious patients also experience benefits, with higher self-efficacy being linked to an amelioration of patients' quality of life, and adjustment to and satisfaction in their own role (Merluzzi et al., 2001).

1.7.13 Decision-making between patients and family caregivers in palliative care

A dearth of research presently exists pertaining to decision-making as a potentially equitable process between patients and family caregivers in palliative care.

Traditionally, patients have been conceptualised as the sole decision-makers with family caregivers having been conceptualised as exclusively supportive to the decisions of patients. In actuality, family caregivers can hold differing opinions regarding patients' treatment preferences, which can cause conflict between them (Le Blanc et al., 2018). Recent research, however, suggests that patients and family caregivers can be flexible to the wishes of one another, and indeed accommodate for one another

within decision-making processes (Mulcahy Symmons et al., 2023). This indicates that both parties are aware that the wishes of their counterpart may be different to their own, and in accommodating their counterpart's wishes, mutual support occurs. While some research cautions healthcare professionals to be wary of 'invisible family influence' on patient decision-making (Laryionava & Winkler, 2021), and other studies emphasising the need for family caregivers to be central in decision-making processes (Aoun et al., 2017; Dionne-Odom et al., 2019), there is discordance in the literature regarding family members' motivations and effectiveness in decision-making. The present study is therefore contributory to the gaps in the literature, as little is known about how patients and family caregivers mutually support one another in making decisions pertaining to palliative care and the end-of-life of the patient.

1.7.14 Mutual support between patients and family caregivers in palliative care

Despite previous research making inferences to the existence and functioning of mutual support between patients and family caregivers in palliative care, few studies have explicitly referred to it as such. In order to address the literature surrounding the topic, pre-existing theoretical models pertaining to familial functioning in the face of difficult circumstances must be discussed in order to ascertain the potential dynamics that exist within the contexts examined. Mutual support has been examined in different contexts, such as the mutually supportive relationships between parents of children with chronic illnesses (Sarancha et al., 2022), between family caregivers of individuals with psychotic disorders (Chien & Norman, 2009) and simply, between spouses (Knudson-Martin, 2013).

Mutual support within the context of the patient and family caregiver relationship in palliative care, however, is underreported. The present study required investigation into mutual support specific to the patient and family caregiver relationship, and therefore examining how mutual support functioned within these contexts was insufficiently explanatory. As such, investigating the dynamics surrounding mutual support within the patient and family caregiver dynamic was pursued in order to supply more appropriate explanation of the mechanisms functioning within this specific relationship. Dimensions of mutual support have been described throughout a priori literature on patients and family caregivers in palliative care such as reciprocal

support in dyadic coping (Von Heymann-Horan et al., 2019), reciprocal information seeking from one another (Andershed & Ternestedt, 2001) and reciprocal encouragement (Ayers, 2007). In order to approach mutual support, an understanding of these theories is necessary.

The delineation of dyadic coping and mutual support requires clarification as while mutual support and dyadic coping feed into one another, key differences between them exist. In dyadic coping, dyad members communicate with each other during stressful periods in a number of ways dependent on personality factors and circumstances, displaying their emotional state to their partner immediately or belatedly, explicitly or implicitly, and through direct, explicit and verbal means or indirect, non-verbal means (Badr et al., 2010; Bodenmann et al., 2007).

The message received from these communications are then perceived and translated by the communicator's counterpart, dependent on the receiver's circumstances and personality factors. There is therefore a large margin for error pertaining to the accuracy of these communications, and as such, discrepancies between dyads in terms of the success of their dyadic coping (Bodenmann et al., 2007). While the presence or absence of dyadic coping can act as a mechanism that prompts or inhibits mutual support, is not mutual support itself. Dyadic coping pertains to the emotional state resulting from a presence or absence of mutual support, particularly open disclosure, however it does not describe the actions, interactions and behaviours that comprise mutual support.

An additional theory that provides insight into the mechanisms of mutual support is that of a dyad striving for coherence to understand one another. For example, Andershed and Ternestedt's (2001) theoretical framework provides explanation as to the need for patients and family caregivers to enlighten one another, through sincerity and openness, in order to ameliorate the efficiency of support between them. This theoretical framework describes relatives' involvement in palliative care states that family caregivers are 'in the dark' or 'in the light' in terms of the knowledge they hold regarding the patient's illness, treatment, emotional state and needs. This framework describes how family caregivers and patients who work in a partnership can enlighten one another in how to have meaningful involvement in the lives of one another during this period and how to provide the patient with an 'appropriate' end of life and death.

In concurrence to what is known on mutual adaptation (see above section), connection, openness, mutual respect and sincerity are described by Andershed and Ternstedt (2001) as key components in moving patients and family caregivers into 'the light' in terms of providing intuitive, effective care and support to one another. While this theory supplements our understanding of mutual support, this theory also includes the healthcare professional as part of the contributory triad to the patient's wellbeing. Thus, it is difficult to attribute this theory to patients and family caregivers alone, providing further justification for the present study.

An additional framework, as developed by Ayers (2007), outlines a model of "reciprocal encouragement" in 'partnership' between patients and family caregivers in palliative care. This theory too ameliorates understanding of the relationship between patients and family caregivers in palliative care, by underlining the importance of a 'like-minded alliance' and a shared reality formed through empathy and understanding of one another (Ayers, 2007). Thus, reciprocated encouragement and hopefulness was shown to lead to shared adaptation, which could certainly be captured under the term 'mutual support' as described in the present study. While elements of mutual support have been captured by a priori literature, the need to capture, organise and categorise the full scope of mutual support was required. The dearth of literature on mutual support and the variation in terms for mutual support in previous research provides justification for the present study, which aims to describe mutual support, identify and outline its barriers and facilitators, and illustrate its role within decision-making processes.

1.8 Thesis structure

This thesis comprises eight chapters. Chapter one has defined key terms and outlined the background, justification, aims, research questions, scope, and context of the study. This chapter also provides an extensive review of literature pertaining to the topic of investigation. Chapter two describes a systematic review and synthesis of the evidence carried out in order to ascertain what a priori literature pertaining to mutual support has been published. Chapter three outlines the methods used in undertaking the study. Chapter three presents a full account of the study procedures from ethical

approval to the end of the analysis. Ethical considerations in undertaking the study and a critique of the strengths and limitations of the methods and procedures are also communicated in chapter three.

Chapters four, five, and six comprise the finding chapters of the thesis. Chapter four reports on processes of mutual support between patients and family caregivers. Chapter four also outlines the key behaviours, actions, and interactions that were found to constitute mutual support between patients and family caregivers in the study. Chapter five provides an account of the key barriers to and facilitators of mutual support between patients and family caregivers, and chapter six reports on decision-making in palliative care for the patients and family caregivers in the study in the context of mutual support. Chapter seven is the discussion chapter of the thesis and discusses the key findings reported in chapters four, five, and six. Finally, chapter eight concludes the thesis and provides recommendations for research, policy, and practice in palliative care based on the findings of the research.

Chapter 2: Systematic Review

Published Works List – Chapter 2: Systematic Review

Figure 2. *PRISMA flow chart of systematic review** **32**

Table 1. *Summary of studies** **34**

Sections from 2.1 to 2.1.6*

*Published in McCauley et al. (2021) (Appendix A)

Chapter 2: Systematic review

2.1 Systematic review

For the purpose of the present study, a systematic review on mutual support between patients and family caregivers in palliative care (McCauley et al., 2021) was carried out to identify and synthesise literature published pertaining to mutual support between patients and family caregivers in palliative care. The article published pertaining to this review can be found in Appendix A under 'Published Works'. This systematic review was the starting point of the study, allowing the researcher to both review the pre-existing evidence and to justify the need for the present study.

While systematic reviews pertaining to dyadic adjustment (Brandao et al., 2017) and coping (Traa et al., 2015) have been previously undertaken, no systematic review seeking to investigate the processes that underpin mutual support in the context of palliative care had been carried out prior to the present study. The present study aimed to seek evidence pertaining to the actions, interactions and behaviours that comprise mutual support, and, while acknowledging their interaction, differentiate this mechanism from emotional processes such as dyadic coping. The full scope and potential of the reciprocal dimensions of caring and support had not previously been mapped out. This provided clear justification for the execution of this systematic review.

2.1.1 Aim of systematic review

The purpose of the systematic review was to systematically identify and examine original evidence on mutual support between patients and family caregivers in palliative care. The review aimed to identify processes of mutual support between patients and family caregivers in palliative care and describe factors that contribute to or obstruct mutual support between patients and family caregivers in palliative care.

2.1.2 Methods of systematic review

A systematic review of original peer-reviewed studies published in full and in English between January 2000 and the end of March 2020 was conducted, pertaining to

mutual support between family caregivers and patients in palliative care. The systematic review was undertaken in accordance with the Joanna Briggs Institute (JBI) manual for evidence synthesis (Peters et al., 2015; Pearson et al., 2005), and employing the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) framework for reporting reviews (Moher et al., 2009) for clarity. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (figure 2, pg. 32) was used to map out the number of records identified, included and excluded, and the reasons for exclusion. The review was carried out between January 2020 and March 2020.

2.1.2.1 Search strategy

The search was conducted using the following databases: Medline; CINAHL; Embase; AMED; PsycINFO; and PsycARTICLES. Search term pathways used in electronic searches were as follows: Palliative care / terminal care / hospice care / end of life care / palliative approach / advanced illness / serious illness / progressive illness 'AND' family carer* / family caregiver* / primary caregiver* / primary carer* / patient* / family* 'AND' mutual support / support exchange / reciprocal support / reciprocity. The asterisk in this case was used to capture the plural case of these terms. The above search terms were chosen in order to capture studies comprising patients and/or family caregivers in palliative care living with advancing non-curable illness. With respect to mutual support, the search terms were used to capture reciprocity and exchange of support between patients and their family caregivers.

2.1.2.2 Inclusion / exclusion criteria

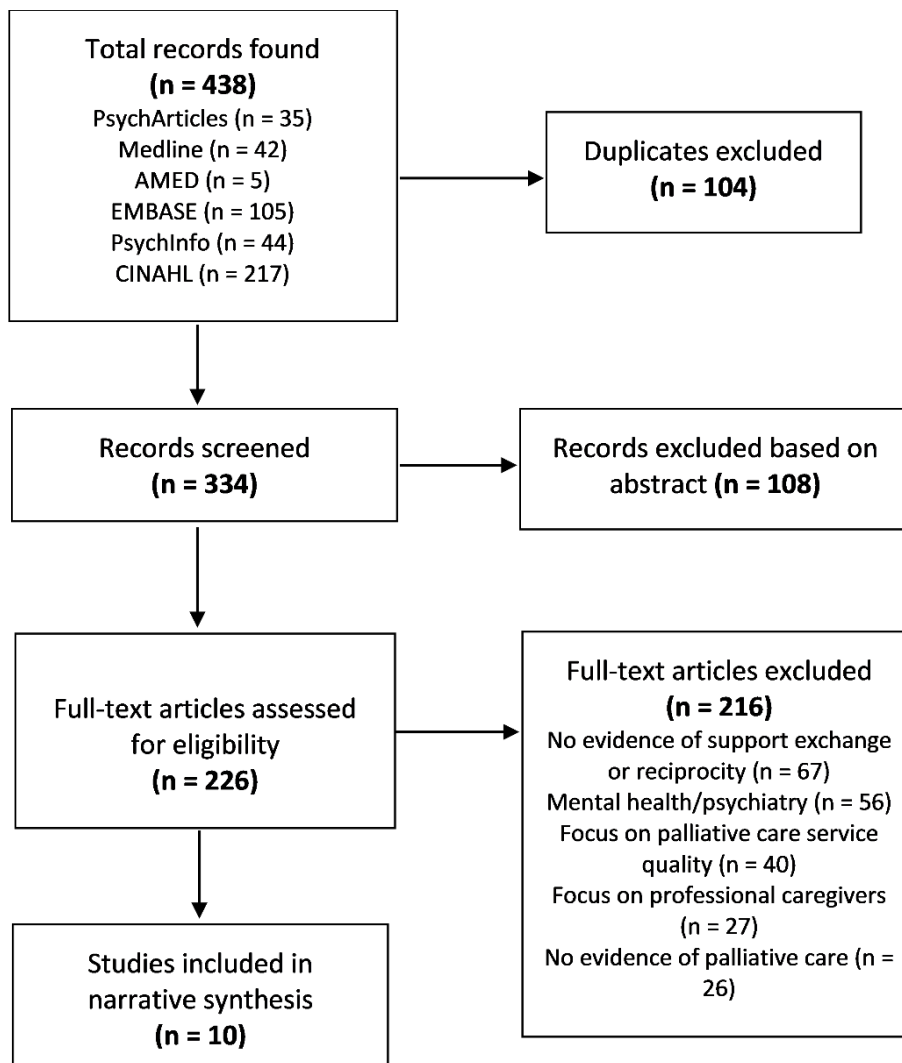
Original empirical peer-reviewed studies that reported on mutual support and/or reciprocity between patients and family caregivers and where it was evident that patients and/or family caregivers had received or were receiving palliative care, were included. Palliative care was defined as treatment which aims to meet the physical, social, and emotional needs of patients with clearly advancing, non-curable conditions, and their caregivers. Studies which sampled both patients and family caregivers, and studies that sampled only patients or only family caregivers were included once the

data generated pertained to mutual support or reciprocity between patients and family caregivers. Literature that was not original peer-reviewed published studies (i.e., grey literature) and studies not published in full and in English were excluded. Given the aims of the review, appraisal pertaining to validity and reliability standard in systematic reviews of interventions was not appropriate. The protocol of the systematic review was not to exclude on the basis of evidence level because studies to answer the review questions were as to be expected empirical studies which ranged in evidence level (e.g., cohort studies, qualitative studies, etc). Hence, any original study that met the inclusion criteria regardless of study design was included.

2.1.2.3 Extraction

The author ran the search and completed a first screen of all titles and abstracts. The author and the author's PhD supervisor then independently screened each title and abstract based on the inclusion/exclusion criteria. For articles that were deemed to possibly meet the inclusion criteria, full texts of these articles were retrieved by the author and read independently by the author and the author's PhD supervisor. Any disagreements regarding inclusion at this point were resolved through discussion and further review of the article. Figure 2 (p. 32) outlines the PRISMA flow chart of the conducted review including extraction at each stage of the review. Table 1 (pgs. 34-36) outlines the studies that met the inclusion criteria for the review, and which were then synthesised (please see section 2.1.2.5 for detail on the synthesis).

Figure 2. *PRISMA flow chart of systematic review**



*Published in McCauley et al. (2021)

2.1.2.4 Quality assessment

The quality of each selected study for inclusion was assessed by using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers tool (Kmet et al., 2004). This tool allows for a systematic and replicable method of assessing the quality of studies from a variety of methodological designs. Studies are given a quality assessment score based on a 14-item checklist for quantitative studies and a 10-item checklist for qualitative studies. Quality rating scores range between 0-1 for each study. The author used this tool because it allowed for the comparison of quality across selected studies. Factors that impacted upon the appraisal of the quality of studies included the appropriateness of the study design, the appropriateness of the sample size, the sampling strategy, the description of the analytical methods and the sufficiency of the reporting of results. The quality of each included study was independently assessed by the author and the author's PhD supervisor and where scores differed, the central value was taken. The quality of studies ranged from adequate to strong. Table 1 (pgs. 34-36) includes the quality metric for each study included in the systematic review.

Table 1: Summary of studies*

Study	Participants	Location	Methods	Study Aims	Findings on the topic	Quality
Ando et al., 2019	n=26 (26 ALS patients)	Hospital outpatient neurology clinic: Liverpool, UK.	Qualitative: thematic analysis; semi- structured interviews	To explore ALS patients' concerns that relate to quality of life for people with ALS.	Significant others provided physical care to patients and supported them emotionally in their illness. Patients sought to minimise the impact of limitations and burden associated with ALS on significant others.	.725
Badr et al., 2010	n=482 (191 female metastatic breast cancer patients, 191 male partners)	Medical setting not stated: Specific location not stated, USA	Quantitative: prospective longitudinal; stress, dyadic adjustment and coping self-report measures	To evaluate whether common dyadic coping was associated with less cancer-related distress and greater dyadic adjustment for female metastatic breast cancer patients and their male partners.	Patients discussed their distress with partners more often than partners discussed their distress with patients. Common positive dyadic coping resulted in better dyadic adjustment for the dyad. Negative dyadic coping resulted in an increase in distress for both patients and family caregivers and a decrease in dyadic adjustment for patients and their family caregivers.	.875
Badr & Taylor, 2006	n=25 (13 lung cancer patients (n=12 metastatic/advanced cancer), 12 spouses)	Cancer centre: Texas, USA	Qualitative: grounded theory; semi-structured interviews	To examine the effect of lung cancer on the spousal relationship.	Dyads experienced a wide variety of social constraints including denial, avoidance and conflict that hindered open spousal communication. Despite these constraints, participants who talked openly with each other about their relationships reported fewer constraints and better communication about cancer.	.825
Gardner, 2008	n=70 (35 advanced cancer patients, 35 spouse caregivers)	Cancer centre: Specific location not stated, USA	Qualitative: grounded theory; semi-structured interviews	To investigate processes of care, support, communication, and search for meaning between older adults living with advanced and terminal cancer, and their caregivers.	Concerns about treatment and illness trajectory were common for both patients and family caregivers but were not always addressed by the dyad. Couples supported each other by expressing hopefulness, acknowledging likelihood of loss, and constructing a shared view of their circumstances.	.825

Lo et al., 2013	n=556 (278 metastatic/advanced cancer patients, 278 spouse caregivers)	Oncology outpatient clinics: Toronto, Canada	Quantitative: cross-sectional cohort study; structural equation modelling; examines the emotional states of psychological self-report measures relating to distress, burden, and social relatedness.	To test a heuristic model which cancer patients and their caregivers in an interdependent relational system.	Non-disclosure of negative feelings resulted in maladaptive communication and coping for both patient and caregiver. Family caregivers were more distressed by patients' distress than patients were distressed by caregivers' distress.	.825
Persson & Sundin, 2008	n=12 (12 family caregivers of advanced lung cancer patients) (mixture of partners (of a couple) and adult children)	Medical setting not stated: Stockholm, Sweden	Qualitative: phenomenology (hermeneutic); semi-structured interviews	To explore the meaning of family caregivers' lived experiences of their situation six months after a family member had been diagnosed with inoperable lung cancer.	Caring for a family member with advanced cancer resulted in feelings for family caregivers of increased closeness to patients, and but also in loss of intimacy and reciprocity between patients and family caregivers. Family caregivers suggested that their relationship with their ill family member was no longer reciprocal because of the responsibilities assumed by them as family caregivers.	.65
Rocío et al., 2017	n=24 (12 advanced cancer patients, 12 family caregivers) (family caregivers – mixture of family members and friends)	Palliative care unit at a national cancer institute: Bogota, Columbia	Qualitative: phenomenology; semi-structured interviews	To explore the patient/family caregiver experience during the transition from hospital palliative care to home.	Family caregivers supported patients by providing physical and emotional care to them. The bond between patient and family caregiver became strong and insular as both managed their shared crisis. Family caregivers had concerns about coping as patients became more dependent on them.	.625
Stamataki et al., 2014	n=53 (53 family caregivers of cancer patients) (mixture of family members and friends)	Cancer centre: Manchester, UK	Qualitative: longitudinal; semi-structured interviews	To investigate the experience of family caregivers of patients with cancer across four timepoints in a 12-month period including palliative care.	Family caregivers reported that mutual recognition and sharing of the cancer experience strengthened the patient-caregiver relationship. How well family caregivers felt they were coping depended on how well they felt their partner was coping. Conflict between patients and family caregivers also arose as a result of patient irritability and behaviour change.	.80

Von Heymann-Horan et al., 2019	n=598 (340 cancer patients, 258 family caregivers) (family caregivers were a mixture of partners (of a couple) and adult children)	Hospital oncology department: Copenhagen, Denmark	Quantitative: randomised controlled trial: anxiety, depression, and coping self-report measures	To investigate whether a specialised palliative care and dyadic psychological intervention increased aspects of dyadic coping in patients with advanced cancer and their caregivers; to investigate whether aspects of dyadic coping mediated significant intervention effects on caregivers' anxiety and depression.	The Intervention significantly Increased dyadic coping (e.g., shared problem solving) in patients and caregivers, and stress communication by partner caregivers. Common aspects of dyadic coping, and stress communication did not mediate significant intervention effects on caregivers' anxiety and depression.	.875
Wittenberg-Lyles et al., 2011	n=30 (30 non-familial related caregivers of palliative care patients)	Urban hospice program: Specific location not stated, Western USA	Qualitative: a priori coding; semi-structured interviews	To explore the transactional nature of reciprocal suffering by examining caregivers' concerns.	Family caregivers reciprocated in feelings of distress when caring for patients. Caregivers placed more emphasis on patients' physical wellbeing than on their own physical wellbeing.	.75

*Published in McCauley et al. (2021)

2.1.2.5 Synthesis

A narrative synthesis (Popay et al., 2005; 2006) of the selected studies was conducted. A narrative synthesis is used to synthesise evidence from studies that are heterogenous in design and does not intend to transform data beyond the findings of the primary studies (Popay et al., 2005; 2006). It adopts a textual approach to the process of synthesis to tell the story of findings from the included studies. First, the author looked exhaustively at the evidence in each study that captured and/or shaped processes of mutual support between patients and family caregivers, including factors that enabled or restricted mutual support between patients and family caregivers. The author then collated and summarised the evidence from each study. Next, the author and the author's PhD supervisor explored relationships in the data, by comparing the data both within and across the studies. Looking iteratively for similarities and differences in the data both within and across studies helped the author identify the evidence that more fully encapsulated key processes of mutual support and the factors that impacted on it. The author then grouped findings into categories that best described key processes of mutual support and/or key factors that shaped mutual support. Both the grouping of findings into categories and the labelling of the categories were decided upon by mutual agreement between the author and the author's PhD supervisor.

2.1.3 Findings of systematic review

Ten studies met the inclusion criteria for the review and were included in the synthesis. The studies extracted varied in scope, design and in their aims (see Table 1, pgs. 34-36). Of the studies included, seven were qualitative (Ando et al., 2019; Badr & Taylor, 2006; Gardner, 2008; Persson & Sundin, 2008; Rocío et al., 2017; Stamataki et al., 2014; Wittenberg-Lyles et al., 2011) and three were quantitative including one randomised-controlled trial (von Heyman-Horan et al., 2019), one longitudinal-cohort study (Badr et al., 2010) and a cross-sectional cohort study (Lo et al., 2013). The studies were conducted in the UK (Ando et al., 2019; Stamataki et al., 2014), Canada (Lo et al., 2013), Denmark (von Heyman-Horan et al., 2019), Sweden (Persson & Sundin, 2008),

Colombia (Rocío et al., 2017) and remainder in the United States (Gardner, 2008; Badr & Taylor, 2006; Badr et al., 2010; Lo et al., 2013).

All studies sampled participants through healthcare settings including a hospital oncology department (von Heyman-Horan et al., 2019), a neurology outpatient clinic (Ando et al., 2019), an oncology outpatient clinic (Lo et al., 2013), specialist cancer centres (Badr & Taylor, 2006; Gardner, 2008; Stamataki et al., 2014), a hospital palliative care unit (Rocio et al., 2017), and a hospice (Wittenberg-Lyles et al., 2011).

Family caregivers were caregivers of patients with cancer only in all studies except one (Wittenberg-Lyles et al., 2011) which also included caregivers of people with other illnesses.

None of the studies found reported exclusively on mutual support between patients and family caregivers in palliative care and only one study (Gardner, 2008) aimed from the outset to investigate processes of support and care between patients and family caregivers. Across nine of the 10 studies that included carer participants in the sample, family caregivers were reported as spouses (Badr & Taylor, 2006; Gardner, 2008; Lo et al., 2012), partners of a couple (Badr et al., 2010), a mixture of family members and friends (Rocio et al., 2017; Stamataki et al., 2014), a mixture of partners (of a couple) and adult children (Persson & Sundin, 2008; von Heymann-Horan et al., 2019), and as non-familial caregivers (Wittenberg-Lyles et al., 2011). The narrative synthesis of the evidence resulted in categorisation of the findings into themes/categories which were labelled and reported in sections 2.1.3.1 to 2.1.3.5.

2.1.3.1 Constructing a shared view

A common way in which patients and family caregivers supported one another was through mutual acknowledgement and understanding of the challenges they both faced (Ando et al., 2019; Badr & Taylor, 2006; Gardner, 2008; Rocio et al., 2017; Wittenberg-Lyles et al., 2011). Shared acknowledgement and understanding were important when patients and family caregivers received new information about the patient's trajectory and/or when the patient's physical condition had changed (Wittenberg-Lyles et al., 2011). Indeed, mutual understanding of the situation at hand enabled patients and family caregivers to communally appraise treatment options and

make decisions about care in a timely manner (Badr & Taylor, 2006; Rocio et al., 2017). Consensus among patients and family caregivers in the decision-making process was a feature of positive dyadic coping between patients and family caregivers (Badr et al., 2010; Stamataki et al., 2014; von Heymann-Horan et al., 2019). However, consensus also featured (inversely) in the context of mutual avoidance (Badr et al., 2010; von Heymann-Horan et al., 2019).

2.1.3.2 Shared positivity

Mutual acknowledgement and understanding were in most cases underpinned by patients' and family caregivers' efforts to foster optimism for each other (Badr et al., 2010; Badr & Taylor, 2006; Gardner, 2008; von Heymann-Horan et al., 2019). Shared positivity was perceived as being mutually beneficial because it enabled both patients and family caregivers to maintain hope for the future (Gardner, 2008). Remaining positive for each other was also framed by acknowledgement of past positive experiences they had shared and were grateful for (Gardner, 2008). Indeed, remaining positive as a unit assisted patients and caregivers to adjust to changing circumstances (Badr & Taylor, 2006; Gardner, 2008) and adjusting well together was in some cases, a latent dimension to how patients and family caregivers supported each other (Badr et al., 2010; Gardner, 2008; Stamataki et al., 2014).

Shared positivity was a feature of positive dyadic coping and was generally associated with both better dyadic adjustment and less illness related distress for both patients and family caregivers (Badr et al., 2010). However, due to the perceived importance patients place on a shared positive outlook, caregivers sometimes felt it necessary to remain visibly optimistic for patients even in the face of significant concerns (Gardner, 2008). In addition, caregivers' compartmentalisation of negative emotions and their positive emotional support of the patient could result in emotional burnout in caregivers (Wittenberg-Lyles et al., 2011). Importantly, the wider family encouragement of patient and family caregiver shared positivity helped patients and family caregivers sustain their positive support and encouragement of one another (Lo et al., 2013; Rocio et al., 2017). Increased support from members of the wider family alleviated caregiver distress and the degree to which patients perceived themselves a

burden on the family caregiver (Lo et al., 2013; Rocio et al., 2017). The presence of other family member support allowed for greater emotional engagement between patients and their family caregivers (Lo et al., 2013). By contrast, in situations where support from the wider family was reported as absent, family caregivers reported feeling alone and difficulty in remaining positive for the patient (Wittenberg-Lyles et al., 2011).

2.1.3.3 Shared distress

Both patients and family caregivers reported distress during the course of illness (Ando et al., 2019; Badr & Taylor, 2006; Gardner, 2008; Lo et al., 2013; Stamataki et al., 2014; von Heymann-Horan et al., 2019; Wittenberg-Lyles et al., 2011). Family caregivers' observation of the patient in physical and emotional distress caused significant emotional distress for family caregivers (Persson & Sundin, 2008). Emotional distress encountered by family caregivers had the capacity to escalate patients' emotional distress (Ando et al., 2019; Badr & Taylor, 2006; von Heymann-Horan et al., 2019) and stressful situations encountered by both patients and family caregivers was perceived to increase distress for each other (von Heymann-Horan et al., 2019). Overall, patients and family caregivers were interdependent for perceived emotional distress. Escalation of distress for patients and family caregivers was associated with common negative dyadic coping (Stamataki et al., 2014; von Heymann-Horan et al., 2019) and poor adjustment to different and/or new roles (Badr & Taylor, 2006; Gardner, 2008; von Heymann-Horan et al., 2019; Wittenberg-Lyles et al., 2011). For example, distress for both patients and family caregivers arose from their concerns about financial matters or change in roles, with some family caregivers having to cease or limit their professional roles because of caregiving duties, with some being forced to prepare for the financial burden arising from providing care and anticipated funeral expenses (Ando et al., 2019; Badr & Taylor, 2006; Stamataki et al., 2014). Perceived distress about the future was also shared because of mutual concern about how each other would cope with further deterioration in the patient's health (Ando et al., 2019). Shared distress in the absence of close relatedness resulted in an escalation of negative feelings toward each other (von Heymann-Horan et al., 2019).

Some patients and family caregivers sought to conceal their concerns for the benefit of each other (Ando et al., 2019; Badr & Taylor, 2006; Gardner, 2008). Non-disclosure by family caregivers was perceived effective by family caregivers to help the patient maintain a positive outlook for the future (Gardner, 2008). However, reluctance to disclose feelings of distress to one another could result in both patients and family caregivers internalising their distress (Badr & Taylor, 2006; Gardner, 2008). Internalisation of distress by patients and family caregivers could then undermine mutual support and increase tension between patients and family caregivers (Badr & Taylor, 2006). In some cases, patients reported frustration and an increase in conflict between them and their family caregiver if patients perceived that their family caregiver avoided communicating their distress to them or did not reciprocate in disclosure of distress (Badr & Taylor, 2006).

2.1.3.4 Negotiating new roles

Both patients and family caregivers acknowledged the challenge of adapting to their new and/or altered roles as a care recipient or caregiver (Badr & Taylor, 2006; Gardner, 2008; Stamataki et al., 2014; Wittenberg-Lyles et al., 2011). Adjusting to the responsibility for the care and pain management of the patient was particularly challenging for some family caregivers (Persson & Sundin, 2008; Rocio et al., 2017) and they struggled when their efforts did not alleviate the patient's suffering (Stamataki et al., 2014). For both patients and family caregivers, the process of adapting to new roles included accepting the need to relinquish previously held professional roles (Badr & Taylor, 2006; Stamataki et al., 2014) and negotiate the conflict arising from changing roles with their partner (Gardner, 2008; Wittenberg-Lyles et al., 2011). Both patients and family caregivers reported change in the balance of power and control between them (Badr & Taylor, 2006; Gardner, 2008; von Heyman-Horan et al., 2019; Wittenberg-Lyles et al., 2011). Perceived change in balance of power was associated with role reversal, for example, in cases where those who were previously dependent on the other became the caregiver (Badr & Taylor, 2006; Gardner, 2008; von Heyman-Horan et al., 2019). However, reciprocal support between patients and family caregivers was

also expressed even when patients and caregivers had exchanged dependent roles (Wittenberg-Lyles et al., 2011).

Some family caregivers indicated that adapting to their new role as a family caregiver was hindered by a lack of social relatedness (Lo et al., 2013) or support from the wider family (Wittenberg-Lyles et al., 2011). Insufficient support from other members of the family as perceived by family caregivers, frustrated family caregivers particularly in situations where support from the wider family was perceived as tokenistic by the family caregiver and was limited primarily to when death of the patient was imminent (Wittenberg-Lyles et al., 2011). Feeling unsupported by other family members made family caregivers feel isolated and/or lacking in self-efficacy in their role as a family caregiver (Persson & Sundin, 2008; Stamataki et al., 2014; Wittenberg-Lyles et al., 2011).

2.1.3.5 Discrepancy in mutual support

Discrepancies existed among patients and family caregivers in terms of supporting one another. Family caregivers were less likely to communicate their distress to patients compared to how often patients communicated their distress to them (Badr et al., 2010). Some patients rated their family caregivers more positively than the family caregivers rated the patient in terms of ability to give support (Badr et al., 2010). Some family caregivers viewed their needs as secondary to those of their family member whom they cared for (Badr & Taylor, 2006) and sacrificed their own interests in the process of caring (Ando et al., 2019; Persson & Sundin, 2008). Family caregivers strove to conceal their concerns from patients to remain 'strong' for patients (Stamataki et al., 2014) even though they revealed their concerns to healthcare professionals and other members of the family (Badr & Taylor, 2006; Gardner, 2008). Patients also valued their family caregiver's wellbeing over their own and they concealed their physical symptoms in their effort to alleviate family caregiver burden (Ando et al., 2019). Patients' and family caregivers' ability to support one another was also shaped by how patients and family caregivers reciprocated or did not reciprocate in their spiritual support of one another (Gardner, 2008; Wittenberg-Lyles et al., 2011). A shared emphasis on spirituality was a dimension to enabling patients and family caregivers to

support one another (Wittenberg-Lyles et al., 2011). Conversely, differences or conflict between patients and family caregivers on the relevance of spirituality meant that offers of spiritual support by one to the other were judged ineffective (Gardner, 2008).

2.1.4 Discussion of systematic review findings

This review aimed to identify processes of mutual support between patients and family caregivers in palliative care and to describe factors that can contribute to or obstruct mutual support between patients and family caregivers in palliative care. As stated, none of the studies found focused solely on mutual support between patients and family caregivers in palliative care and only one study had aimed from the outset to explore processes of mutual support between patients and family caregivers. Nearly all studies were conducted in developed western countries which could affect verbal expressions of mutuality and expression of support, or indeed propensity to engage in research focused on relationships and family support. Overall, the literature reviewed indicated that patients and family caregivers can support one another by mutually acknowledging the challenges they face, by fostering optimism for one another, and by negotiating together the change in their roles. However, in order to minimise causing distress for each other, patients and family caregivers may not routinely communicate their distress to each other or reciprocate in disclosure of distress. A lack of mutual disclosure can result in conflict between patients and family caregivers. Distress for both patients and family caregivers can arise in part, from the challenges associated with changing roles. Family caregiver distress can escalate if they feel unsupported by other members of the family.

The findings of the review resonate with the wider literature, including literature beyond palliative care. A study on distress and quality of life in patient and caregiver dyads facing stem cell transplant in cancer (Sannes et al., 2019) also found distress among caregivers and patients to be interdependent and that patients' physical wellbeing accounted significantly for caregiver wellbeing. Correlation of symptoms between stroke survivors and their family caregivers has also shown that family caregivers experience increased emotional distress caring for their family member when they perceive their family member becoming more severely affected by their

illness (Cameron et al., 2011). In stroke survivorship, family caregiver optimism also has the capacity to alleviate patient distress (Chung et al., 2016).

The findings of the review point to how patient and family caregiver support of one another in palliative care can be mediated by the wider family. Support from other family members can have a positive effect on both patients and family caregivers but a lack of support from other family members can be particularly stressful for family caregivers and make it more challenging for them in their caregiving role. These findings are consistent with palliative care literature (Park et al., 2012; Selman et al., 2015). Understanding the processes of mutual support between patients and family caregivers in palliative care also needs attention to the wider social contexts of patients' and family caregivers' experiences in palliative care and how these contexts impact on how patients and family caregivers reciprocate in their support of one another. Support exchange between patients and family caregivers in palliative care is also mediated by contexts beyond the dyad that shape patients' and family caregivers' capacity to support each other.

The findings of the review highlight the complex nature of relations between patients and family caregivers in palliative care. Shared understanding and positivity can enable patients and family caregivers adjust to progressive illness and engage effectively in the decision-making process. However, patients and family caregivers also experience distress and do not routinely communicate their concerns to each other. In some cases, disclosure can be more challenging for family caregivers. In practice, attention should focus not only on alleviating distress for patients and family caregivers but also on how patients and family caregivers can best communicate their distress to each other. Facilitating patients and family caregivers in this context has potential not only to alleviate distress for both patients and family caregivers but also to increase concordance between patients and family caregivers in the decision-making process for treatment and care.

2.1.5 Strengths and limitations of the systematic review and narrative synthesis

The systematic review was limited to original peer-reviewed journal publications and excluded all grey literature. Although a search through grey literature might have

identified additional evidence for this review, limiting the review to the above allowed for the objective assessment of the methodological quality of each piece of evidence that was included. A wider 'scoping' review pertaining to mutual support between patients and family caregivers in palliative care may have broadened findings further. Another limitation of the systematic review is that it was limited to studies reporting on patients with clearly advancing conditions likely to result in their death. Palliative care can serve the needs of people with life-limiting or life-threatening illness at different stages of non-curable conditions. A systematic review of the evidence in palliative care along the full illness trajectory would have served to expand further on the review findings. Due to the small number of studies which addressed this topic, in addition to studies that sampled both the patient and family caregiver, the author included studies that sampled only patients or only family caregivers once the data generated pertained to mutual support or reciprocity between patients and family caregivers. Therefore, it is possible that in these studies, the evidence reflects only what patients or only what family caregivers perceived as mutual or reciprocal. Finally, the review limited to a 20-year period. A review from inception to the end period may have extracted other studies that met the inclusion criteria.

2.1.6 Conclusions from the systematic review and narrative synthesis

The studies extracted in the review varied in scope and design. The small number of studies found to answer the review questions combined with broadly very different aims across studies makes it difficult to fully extrapolate the findings. However, the findings of the review have key implications for research and practice. As stated, no study was found in the systematic review that reported exclusively on mutual support between patients and family caregivers in palliative care and only one study aimed from the outset to investigate processes of support and care between patients and family caregivers. A limited focus on mutual support between patients and family caregivers could in part be a consequence of how researchers and healthcare professionals have traditionally conceptualised the roles of patients and family caregivers in palliative care. Although patients and family in palliative care are treated by healthcare professionals and researchers as a 'unit' of care (Connor, 2009; Radbruch

& Payne, 2009), more-often-than-not, patients in palliative care are defined as recipients of care from family caregivers, and family caregivers are defined as providers of support to patients. Research in palliative care that is sensitive to the bidirectional nature of support between patients and family caregivers and to the wider caring and family roles that patients and family caregivers can have in relation to each other, is needed to advance our understanding of mutual support between patients and family caregivers in palliative care.

Literature pertaining to mutual support between patients with advancing non-curable illness and their family caregivers in palliative care has reported primarily from people with cancer and/or their family caregivers. However, palliative care is not limited to people who live with cancer and multiple other diagnostic groupings (e.g., neurodegenerative disease, chronic heart failure, chronic obstructive lung disease, and infectious disease) access palliative care services. Studies pertaining to mutual support between patients with advanced illness and family caregivers in palliative care that extend to other conditions would be beneficial to expand on what we now know about mutual support between cancer patients and family caregivers in palliative care.

The findings of the review suggest that support from the wider family can allow for greater emotional engagement between patients and family caregivers in palliative care and alleviate distress for family caregivers. However, family caregivers' perceived lack of support from other members of the family can make it more difficult for family caregivers to adjust to the demands of caregiving. Research to identify how the wider family can best support the patient and family caregiver in palliative care and alleviate distress for the family caregiver could be beneficial. Indeed, attention to wider socio-cultural contexts in palliative care is necessary. Socio-cultural contexts do shape the experience of death and dying (Kellehear, 2007), which in turn can impact on mutuality between patients and family caregivers in palliative care.

2.2 Chapter conclusion

Evidence in this literature review chapter has shown that patients and family caregivers are emotionally interdependent. It is understood that patients receive support both

formally from palliative care services and informally from their family caregivers. However, less is known about how the patient provides support in general to their family caregiver or indeed the reciprocal dimensions of support between the patient and family caregiver in palliative care. The evidence indicates that patients and family caregivers in palliative care are emotionally interrelated, but little is known about how the patient and family caregiver acknowledge their connected emotional states, mediate their shared distress, and understand the link between supporting one another and their shared distress. Mutual support between patients and family caregivers is an under-researched phenomenon in palliative care (McCauley et al., 2021). How mutual support (or the lack thereof) between patients and family caregivers in palliative care impacts on how they approach decision-making pertaining to treatment and care is not clear.

The study reported in this thesis was justified by the dearth of studies undertaken in the field focused whole or in part on mutual support between patients and family caregivers in palliative care. The systematic review undertaken was evidence that further research was required to identify key domains of mutual support between patients and family caregivers in palliative care, and the factors that facilitate and/or restrict mutual support between patients and family caregivers. Moreover, further investigation of the impact of patient and family caregiver mutual support on patient and caregiver decision-making pertaining to treatment and care was warranted. Understanding better what actions or interactions constitute mutual support between patients and family caregivers and the conditions that impact positively or negatively on patients' and family caregivers' abilities to support one another, can potentially help guide interventions in palliative care focused on enabling supportive relations between patients and family caregivers.

Chapter 3: Research Methodology

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Chapter 3: Research methodology

3.1 Qualitative inquiry

Qualitative research is research that generates findings by procedures that lie outside of quantification by statistical means and is generally focused on human experience and social interactions (Silverman, 2017). Social phenomena that require a depth and richness to the understanding of the study topic are ordinarily suitable for investigation through qualitative methods (Ritchie et al., 2013). Qualitative inquiry is key for explanatory research because it enables the researcher to understand the scope of factors that tend to encompass complex phenomena (Denzin & Lincoln, 2018). Unlike quantitative methods which excel at testing hypotheses, qualitative research allows for the development of new knowledge and allow the researcher to build understanding based on the evidence that unfolds.

3.2 Justifying qualitative methodology for the present study

Palliative care is a field primed for qualitative research methods as the richness and diversity pertaining to the palliative care experience cannot be fully captured by measurement alone. Investigations pertaining to interactions between the patient and healthcare professional, the patient and family member, and indeed the wider family and palliative care services that surrounds the patient and caregiver, as well as the individual perceptions of these interactions, are suitable to qualitative research methods. The use of qualitative research methods in palliative care allows for a comprehensive understanding of the aspects which make up the palliative care experience.

As illustrated by chapter 2, the results of the systematic review undertaken to assess the current knowledge pertaining to mutual support between patients and family caregivers in palliative care is insufficient. Both the scope and quality of previous research that discusses mutual support is insufficient to adequately describe and explain mutual support, with the majority of studies included in the systematic review reporting findings on mutual support as peripheral and not central findings of their studies. Only one of the papers included in the systematic review aimed to investigate

mutual support explicitly. The dearth of knowledge pertaining to mutual support required research methods that would be descriptive and exploratory in nature in order create a foundation of knowledge pertaining to mutual support between patients and family caregivers in palliative care. It was determined that the present study would benefit from the use of qualitative research methods to identify both obvious and latent contexts underpinning mutual support between patients and family caregivers in palliative care.

Qualitative research allows for clarification of questions by participants who may apply their own operational definitions to constructs, for example in the case of the present study, their understandings pertaining to support or indeed mutual support. The researcher's understanding of participants' contexts and of participants' own understanding of the terms they themselves use is pivotal to the researcher's ability to interpret their views and experiences. Allowing participants to apply and expand on their definition of a construct allows for a greater understanding of what these terms mean to the participants. Due to the novelty of the current study, knowledge can be developed through understandings put forth by and expanded by participants. Importantly, qualitative methods are best placed to map out the key domains of patient and family caregiver mutual support in palliative care, both to answer the research questions and potentially inform the basis of qualitative and quantitative research on supportive actions, interactions and behaviours between patients and family caregivers in palliative care.

3.3 Grounded theory methodology

The grounded theory method is a systematic set of techniques and procedures for generating well conceptualised concepts, explanatory frameworks and in some cases, theory from data (Corbin & Strauss, 2015; Foley & Timonen, 2005). It is well suited to investigating poorly understood phenomena. Grounded theory was founded by American sociologists Barney Glaser and Anselm Strauss (Glaser and Strauss, 1967; 2009) in the 1960s during their fieldwork with terminally ill patients.

A grounded theory approach was used because the study was focused on identifying key psychosocial processes, such as participants' actions and behaviours in response to

contexts, that help explain the phenomenon of interest (Corbin & Strauss, 2015), in the case of the present research, mutual support between patients and family caregivers in palliative care. Grounded theory is also an appropriate methodology for the examination of a particular subset of people within a particular social setting (Chun et al., 2019; Johnson & Rowlands, 2012), that is patients and family caregivers in palliative care in the context of the present study. Certain characteristics of grounded theory distinguish it from other qualitative approaches. Data are not just analysed and coded for concepts. Relationships between concepts are actively pursued by the researcher by making comparisons between data. Sampling involves sampling for concepts in the data to build relationships between concepts. Hence, data collection and analysis in grounded theory research are not distinct phases of the research (Charmaz, 2014; Corbin & Strauss, 2015).

Importantly, grounded theory is both an exploratory and explanatory method (Kelle, 2019) suitable to use when explanations for the phenomenon under study have yet to be provided and/or expanded (Creswell & Poth, 2016). The process or phenomenon being examined requires the generation of well conceptualised data that can account for and explain variation in data (Charmaz, 2014). Contemporary grounded theorists work on the basis that data is co-constructed between the researcher and the participants to some degree (Bryant, 2021). Co-construction occurs through the interaction between the participant and the researcher, for example in the interview process (Mills et al., 2006). Hence, investigation is guided by the researcher in response to participants' responses and the findings that emerge in the study.

3.3.1 Grounded theory and pragmatism

The grounded theory approach is closely associated with the philosophy of pragmatism (Dewey, 1929). Pragmatism is based on the tenet that knowledge is created through action and interaction. The application of the grounded theory method in the current study focused on a cohort navigating the challenges of living with life-limiting illness and engaging with palliative care. Based on principles of pragmatism, it is understood that people do not simply act in a habitual way but rather apply reflective thinking that may change the course in their actions and behaviour. Of note, the grounded theory

approach assists in explaining the ways in which the individuals at the core of the research behave in their context (Strübing, 2010). Their actions and behaviours can be dependent on factors such as how they have historically navigated issues, the circumstances in which they live, and the learnings they take from those around them.

3.3.2 Grounded theory and symbolic interactionism

Grounded theory also evolved from symbolic interactionism; an ideology founded on the basis that societies are structured around and maintained by the interactions that take place within it (Blumer, 1969). Symbolic interactionism is based on the assumption that individuals make their own sense of their world and of their experiences through interactions that arise in their communications with others and the meaning that the individual ascribes to each interaction. Meaning is created by and changed for individuals through their evolving interpretation of the actions, reactions, and interactions between them and other individuals and with society at large. In grounded theory, both the participant and the researcher can ascribe meaning to their interaction with others and each other (Corbin & Strauss, 2015) and each interaction between the researcher and participant informs the basis of interaction with subsequent participants of the study (Chamberlain-Salaun et al., 2013).

3.4 Grounded theory appropriateness for the present study

The researcher referred to the research aims to understand why grounded theory was an appropriate qualitative approach with which to conduct the study. The interlinked aims of the study as already outlined were three-fold; 1) To identify and explain key processes (i.e., actions and interactions as shaped by context) of mutual support between patients and family their family caregivers; 2) to identify what factors facilitate and/or restrict mutual support between patients and family caregiver in palliative care; and 3) to identify and explain how mutual support between patients and family caregivers in palliative impacts on their decision-making for care.

The author identified that in order to gain an understanding of the complex relationships and support systems that shape the palliative care experience, descriptive qualitative research would not sufficiently map out and explain processes

of mutual support between patients and family caregivers in palliative care. Due to the novelty of the topic and the lack of existing research on the topic, methodology that goes beyond description to explain processes (Corbin & Strauss, 2015) was required. While descriptive qualitative research reports on participants' perspective and insight, a more heavily conceptualised and explanatory approach was deemed more appropriate. In other words, grounded theory methodology was most appropriate in terms of not only describing, but also *explaining* mutual support between patients and family caregivers in palliative care.

3.5 Ethical considerations for the inclusion of patients and caregivers in qualitative palliative care research

Carrying out qualitative research on sensitive topics is a careful balance between allowing participants to experience the cathartic, therapeutic and empowering repercussions of participation and ensuring that the risk of potential harm to participants is reduced as much as possible (Spencer et al., 2021). The risks are deemed to be worth taking in cases where exhaustive efforts to reduce risks is undertaken, in an effort to undertake research *with* vulnerable cohorts and not *for* them (Chambers et al., 2019). The literature states that with the involvement of invested, skilled and emotionally responsive researchers, the participation of individuals receiving palliative care is not only feasible, but beneficial to many participants given the opportunity to share their experiences.

It is acknowledged that certain groups inevitably require increased monitoring during the research process to avoid risk of emotional distress and any other side effects of participation (Sharkey et al., 2011; Shaw et al., 2020; Sikweyiya & Jewkes, 2013). In the present study, participants were made aware that while the research would not affect their care, the research may go on to contribute to and inform the development of policies and support mechanisms put in place for patients receiving palliative care and their family caregivers. While participation had in the present study no direct benefits with regards to a patient's medical care, involvement in research can still have indirect benefits for participants in palliative care research (Chatland et al., 2021). These benefits can include for example the participants feeling emotionally supported by the

researcher, feeling positive by their contribution to research, and feeling validated in their role as research participants (Chatland et al., 2021) and in their respective roles of patient and family caregiver. A failure to offer people with life-limiting conditions an opportunity to engage in research may deny them a voice and compromise the ethical principle of justice (S. Alexander et al., 2018; S. Alexander, 2010; Gysels et al., 2008).

The author understood that the design of the study was configured to the specific needs of both those in receipt of palliative care services and their family caregiver in mind. As such, the decision was made to allow patients and family caregivers partake in the study together or without their counterpart, as excluding individuals on the basis of their counterpart being too ill, distressed, or simply unwilling to participate was deemed to be unethical. In addition, the exclusion of these participants may have resulted in excluding a cohort of those who had a counterpart that was avoidant of discussions of this nature, acutely ill, or in conflict with the potential participant. Exclusion of these participants was therefore considered highly unethical as these participants would have been both excluded from a potentially therapeutic experience through interview, but additionally, their experience would not have been recorded to assist those in their position in the future. It was established therefore that these participants would be included both as a result of ethical considerations and potential benefit to the rigor and scope of the data.

The research was conducted under the supervision of a PhD supervisor with expertise in conducting qualitative research in palliative care. The skills required to navigate research with medically vulnerable people and their family caregivers with sensitivity were honed and improved under supervision of the author's PhD supervisor. The author's PhD supervisor assisted the researcher in following the processes set out in her ethics application to conduct the research and advised the author on strategies to optimise her ability to engage successfully with both research participants and gatekeepers.

The study also had the direct support of two Consultants in Palliative Medicine at the recruitment sites for the project and who were collaborators for the study. The input and experience of these two collaborators was central both with respect of their ability to give the author access to and build rapport with gatekeepers and to advise the

author in terms of the appropriateness of certain potential participants for the study. They also provided valuable insights into the hierarchical structure of the recruitment sites and how to access particular types of patients in the process of theoretical sampling (please see section 3.10). All of the above assisted the author in minimising any potential disruption to recruitment site activities during data collection.

3.6 Ethics in the research study

3.6.1 Approval by research ethics committees

Ethical approval for this project was granted on 7th of January 2020 by the Research Ethics Committee at St. Francis Hospice Dublin and on the 17th of January 2020 by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee. Amended applications were subsequently made to both research ethics committees due to adaptation of procedures for data collection which was necessary in the context of the COVID-19 pandemic. The amendments were approved on the 29th of September 2020 by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee and on the 22nd of October 2020 by St. Francis Hospice Research Ethics Committee. Ethical approval letters can be found in Appendix H. A Data Protection Impact Assessment was conducted in tandem with research ethics applications and approved by Data Protection Officers at both Trinity College Dublin and St. Francis Hospice Dublin.

3.6.2 Ethics and the gatekeeper role

Palliative care patients participating in qualitative research have reported positive experiences with few reporting any distressing experiences whatsoever (Aoun et al., 2017). However, occasionally gatekeepers may refuse to participate in recruitment, deciding unilaterally that the research being undertaken is likely to cause harm to patients (S. Alexander, 2010; Bonevski et al., 2014). Gatekeepers can be well-intentioned in their efforts but in their perceived responsibility to protect and unburden patients, may exclude certain patients from potential recruitment (S. Alexander, 2010). While the process of gatekeeping may often be helpful in deeming some patients genuinely unsuitable to participate, it can also exclude patients who

both want to and are able to participate. Consideration needs to be made that when excluding a participant due to the perception that it may cause them to be overburdened, it is still appropriate that the potential participant be given the autonomy to exclude themselves only if they concur with this assessment. It is argued by the researcher that it is unethical and inequitable to remove the option of participating in research based on perceptions of anyone but the potential participants.

Overly protective gatekeeping can be a barrier to a large group of this cohort accessing the information to even opt into research, where they may want their voices and experiences to be heard (De Camp et al., 2022). However, over-protection of patients by gatekeepers can be negated by the researcher fostering rapport and trust between them and study gatekeepers. While protective gatekeeping did occasionally arise in the current study, the gatekeepers who assisted in participant recruitment were broadly enthusiastic and helpful once rapport and trust were fostered between the researcher and them. Importantly, fostering trusting relationships with gatekeepers allowed the researcher to gain their insights on potential participants particularly when the author sought to sample particular types of participants as the study proceeded.

3.6.3 Informed consent

Each participant was approached by gatekeepers and given an invitation letter (please see Appendices B and C for patient and family caregiver invitation letters, respectively). Invitation letters were accompanied by a detailed participant information leaflet (please see appendices D and E for patient and family caregiver participant information leaflets, respectively) which explained the study in detail. Each participant gave informed consent to participate before their participation (please see Appendices F and G for patient and family caregiver consent forms, respectively). Participants were informed that involvement in the research would require the researcher having access to the medical files of the patient and contact details for the patient and family caregiver. Gatekeepers in both hospice sites acted as a conduit for communication between the researcher and potential participant until permission from the potential

participant was given to be contacted by the researcher or until the potential participant contacted the researcher.

Permission from participants to contact and introduce the project was independent from consent to participate in the study. The author briefed the potential participant on the project, its aims, and their role as a participant. A follow-up phone call was then organised between each participant and the author. This allowed for potential participants to take time in making an informed decision to either participate or decide to withdraw their contact details. This time also gave patients and family caregivers that intended to participate time to decide whether they wanted to be interviewed individually or together. This buffer period was also intended to be an opportunity for participants to discuss their potential participation together privately so that their decision would not necessarily be influenced by what they perceived the author's or gatekeepers' preferences to be. The author reiterated during the follow-up phone call with potential participants that if they required more time to discuss with each other their participation, they could do so, or if one or both members wished to withdraw, they should feel free to withdraw up until the analysis of their data.

3.6.4 The ethical implications of conducting research in palliative care during the COVID-19 pandemic

In-person contact with medically vulnerable populations carried significant risk due to COVID-19. For example, patients undergoing aggressive or symptomatic treatment for cancer were a group deemed highly susceptible to the virus because of their immunosuppressed state associated with malignancy and/or cancer treatments (Tian et al., 2021). This context resulted in this cohort of patients being at acute risk of viral infection and having poorer outcomes following infection than the general population (Liang et al., 2020). On such evidence and following advice from medical staff at recruitment sites, in-person data collection was not possible for many patient participants. Subsequently, online or telephone interviews were considered by the author an acceptable data collection method.

Restrictions to carrying out in-person data collection with the majority of participants as described later in this chapter also created a barrier to visually identifying distress in

participants during data collection (of which comprised qualitative interviews as detailed in sections 3.11.1 and 3.14). The author ensured that participants were frequently asked throughout their interview if they wished to stop or take a break from the interview, if they were uncomfortable, becoming fatigued, and (in the case of patient participants) if they were experiencing any pain. The author also took care in ensuring that participants did not leave the interview in distress by speaking to them about their experience of being interviewed as part of the debriefing process. The author informed the participants about the counselling service offered by the recruitment site (i.e., hospice) if the participants suggested they would like to speak about their experience further, and promptly informed hospice staff if participants showed any signs of upset or distress during the interview. However, due to the potentially cathartic nature of the qualitative interview (Campbell et al., 2010; Wolgemuth et al., 2015), follow-up support after participation was not requested by any of the participants of the study.

3.7 Data protection

The data protection procedures of this study reflected the data subject rights of the participants. These rights included right of access, rectification, and erasure of their data, right to object to processing based on legitimate or public interest, right to data portability (the right to have their data sent to them in an easily accessible open format), and the right to object to profiling or making decisions about individuals by automated means (European Parliament, 2018). Data were stored in encrypted laptop password-protected folders on OneDrive (General Data Protection Regulation [GDPR] compliant) and hard copy data were stored in a locked filing cabinet at Trinity College Dublin. Transcripts were by procedure returned to participants, but participants could also opt out of receiving their transcript if they so wished. It was stressed to participants in both the participant information leaflets and in preliminary discussions about participation that their consent could be withdrawn at any time before analysis of their data.

3.8 Reflexivity of the researcher

Reflexivity requires taking the understanding gained from reflectiveness and using the learnings gained from this introspection to improve the research processes for both researcher and participant. While reflection entails observing the examined subject alone, reflexivity requires the researcher to observe the examined subject while having an internal dialogue in which they can consider various perspectives on this subject (P. Alexander, 2017). In qualitative research, researchers must be aware that the questions they ask, their subconscious biases, and their intonation inevitably shape the interview process (Hertz, 1996). Researchers themselves affect the research at all stages of the research, and in particular at the design, data collection, and data analysis phases of the research.

It could be argued that researchers undertaking grounded theory studies are highly reflexive and well placed to identify and disprove their own biases for a number of reasons. Key processes of grounded theory, data triangulation and the constant comparison method, are built in mitigators of bias within the methodology. The researcher compares and contrasts similar and different cases, adding rigor and robustness to their theories and allowing them to identify areas in which the knowledge requires supplementation (Mruck & Mey, 2007). Through transparency and the recording of thoughts and reflections through memos (further discussed in 3.11.2), the grounded theory research is likely better placed than other qualitative researchers to 'catch' their biases and to attempt to seek all information on a particular phenomenon, and not just that that supports their hypothesis (Lazenbatt & Elliot, 2005). The lack of explicit hypothesis, in fact, allows grounded theorists to collect all data pertaining to their research question, allowing the lines of enquiry to develop iteratively. As such, biases that a researcher may begin a study with can be altered and loosened through the responses to the open-ended questions asked in grounded theory procedures (Anderson et al., 2016). Lastly, grounded theorists suggest that collaboration in grounded theory will further contribute to the rigor of the data and bias-reduction within the study. The author of the present study implemented the

above recommendations, including memoing, exhaustive attempts to gain variance in the participant cohort and the dataset, and peer-reviewed analysis.

3.8.1 Responsibility of the researcher

In the present study, the author was a research tool and she was prepared to think reflexively throughout the course of data collection and analysis. This was done both by pursuing or discarding ideas through reflective inquiry and by seeking confirmation of the data as data collection and analysis progressed. Importantly, the researcher had to be prepared to be both sensitive and attuned to participants' emotional state in order to observe any undue distress caused to the participant. It is for this reason that the researcher had to be physically and emotionally well to function as a safeguard within the interview process. McClelland (2017) suggests that in discussing issues that require emotional presence and attention, both parties (interviewer and interviewee) may experience emotional repercussions from the engagement. In palliative care, patients and family caregivers often perceive therapeutic benefits of taking part in a qualitative interview (Sivell et al., 2019). However, the effects of such interactions can also impact adversely on the researcher (Fenge et al., 2019). Hence, the author was mindful of her own wellbeing whilst engaging directly with research participants on an ongoing basis, throughout data collection and analysis.

3.9 Participant recruitment

3.9.1 Recruitment sites

Participants were recruited from two hospice sites which constitute a large regional specialist palliative care service in the Republic of Ireland covering an area of ca. 700,000 people (14% of the national population). The regional specialist palliative care service comprises a mix of inpatient, outpatient, day hospice and community-based care. Recruitment took place between July 2021 and May 2022. The majority of participants were recruited through community specialist palliative care teams of the two hospice sites. Other avenues for recruitment from the regional specialist palliative

care service such as outpatient clinics, day hospice, and inpatient hospice, were limited because of COVID-19 restrictions in place.

3.9.2 Participant eligibility criteria

Inclusion criteria for patients were that they be ≥ 18 years old and in receipt of palliative care. Inclusion criteria for family caregivers were that they were also ≥ 18 years old and that they were identified by a patient in receipt of palliative care as their primary caregiver.

3.9.3 Gatekeepers informed about participant selection

The author described inclusion criteria to gatekeepers and stressed to gatekeepers that although it would be intuitive to always pinpoint the most conversational patients and family caregivers as potential participants, this would be disadvantageous to the study. Inviting participants also who were perhaps less extroverted or who may have accessed less formal palliative care services than others was important to gain variation in the sample. The author also stressed to gatekeepers that there was no 'ideal' family unit in mind for the research. Families that had more complex or non-traditional structures such as blended families or co-living arrangements were also perfectly acceptable.

3.10 Sampling: Purposive and theoretical

Participants were initially purposively sampled for variation (e.g., age, life stage, gender, and where possible variation in relationships as exemplified in the preceding section of 3.9), and then in later stages of the study theoretically sampled based on key findings in the data (Corbin & Strauss, 2015). As per the grounded theory method, the author moved back and forth between sampling, data collection and data analysis, and ceased sampling when key findings were well described and saturated, which occurred when new data was no longer adding further meaning to the key findings (Corbin & Strauss, 2015).

In purposive sampling, participants were selected with the research aims in mind and who were best placed to provide answers to the research question. The goal of this stage of sampling was to gather information-rich cases as already described that would give insight into the phenomenon being examined and inform the future routes of inquiry (Draucker et al., 2007). Theoretical sampling then involved sampling for concepts in the data to expand on and saturate key concepts in the data (Foley et al., 2021). This included seeking out participants who had experiences to further provide dimension, to understand, and explain the data. This occurred in the present study in two forms, sampling for types of participants who were missing from the cohort recruited in purposive sampling, and sampling for participants who could uncover information that would fill gaps in the data collected prior. The author, for instance, was required to sample specifically for male caregivers as they were not present in the original purposive sampling cohort. As such, the author worked with medical personnel to identify and recruit patients with/and male family caregivers in order to capture the male family caregiver perspective. In terms of theoretically sampling to address gaps in the data, the author also discussed these gaps with medical personnel who were able to identify individuals that could speak to these data points. For example, by the mid-stage of data collection, obligation was emerging as a key category which comprised in part, participants believing it necessary to support their respective other. Obligation also included participants feeling constrained in their relationship with their respective other because they sometimes felt obliged to agree with their respective other's preferences for care. The author then sampled patients and family caregivers who had already communicated disagreement about their preferences to further interrogate the concepts of obligation and choice, and understand relationships between obligation, choice, and decision making.

3.11 Data collection

3.11.1 Qualitative interviewing

In-depth semi-structured qualitative interviews were undertaken by the author with participants. Data collection allowed for the patient participant to be interviewed on

their own (Appendix I), the family caregiver participant to be interviewed on their own (Appendix J), or for the patient and family caregiver to be interviewed together (i.e., dyadic interview) (Appendix K). The open-ended questions of the interview guides were informed by the systematic review outlined in chapter two (McCauley et al., 2021), by wider literature on patient and caregiver relational decision-making in advanced illness (Foley, 2018), and by public and patient involvement (PPI). The PPI review of the study reported was undertaken by a member (former caregiver) of an established Irish-based palliative care PPI group, AllHPC Voices4Care. From this PPI group, a family caregiver representative reviewed the interview guides for applicability and sensitivity. Once their approval was gained, the interview guides were finalised. In addition, the PPI network in Trinity College Dublin were consulted for their views when developing the interview guides and indeed when formulating the wider study.

The interview guides allowed the participants to describe their experience openly which might otherwise have been inhibited by a highly structured interview guide. They also allowed for consistency in data collection. However, the open-ended questions were essentially a platform from which to probe, prompt, and clarify as the study proceeded. The author began with an awareness and knowledge of pre-existing literature but also remained open to new findings that have not been uncovered thus far, as well as findings that are contrary to previous findings to create new knowledge (Corbin & Strauss, 2015; Timonen et al., 2018). To understand the context in which the participants were interviewed, an early question asked the participants to broadly describe their experiences of palliative care with their respective other. Active listening on the part of the interviewer was particularly important in the early stages of the interviews because it allowed the researcher to encourage the participant and to demonstrate to them that their account was being closely attended to. The interview guides also allowed for the participants to speak freely about their experience at the close of the interview, so as not to exclude any important perspectives that they had not yet communicated. To support contextualisation of the data for analysis, field notes were recorded by the author on key observations of participants' presentation and engagement in the interview. As data collection proceeded, the author began to steadily probe participants but also in many cases, prompt them to expand on

emerging data and to confirm what they had communicated. Each interview conducted in the study was digitally recorded and transcribed verbatim.

3.11.2 Memo taking

Memo taking is an important procedure in a grounded theory study (Birk & Mills, 2015; Montgomery & Bailey, 2007). Memos were reflective points of data taken by the author to account for both data collection and interpretation of the data.

Memos took two main forms. First, a descriptive synopsis of the interview was written quickly after the interview, outlining the main points that had stayed with the author directly preceding it. This highlighted to the author the main concepts that were apparent from the participant's experience. As these main concepts were reiterated to the participant in summary during the member check within the debriefing conversation following the interview, these were also generally verified or clarified by the participant to ensure concurrence of understanding. Hence, a confirmed version of the participant's perspective was recorded in these descriptive memos. The confirmation of participants' meaning lent itself to the confirmability of the study (Korstjens & Moser, 2018; Lincoln & Guba, 1985). Second, the author also utilised memo taking while analysing the data and which is described in section 3.12, pertaining to data analysis.

3.11.3 Interviewing in the context of the COVID-19 pandemic

The impact of COVID-19 during the period of the study required the author to alter data collection procedures. The initial protocol of the study was for interviews to be in-person. However, the author was required to adjust procedures to facilitate remote interviewing (Foley, 2021) as restrictions imposed by COVID-19 made in-person interviews an impossibility in most cases. All participants had been given a choice of an online video-call for their interview using General Data Protection (GDPR) compliant platforms (e.g., Zoom, Microsoft Teams) but only three participants wished for this mode of interview. Despite the enforced alteration to data collection procedures due to COVID-19, the author was satisfied with the findings gleaned from phone interviews

and that they generated the richness and quality of data when compared to the small number of in-person or video-based online interviews undertaken.

Phone interviews still allowed the author to partake in memo taking without disruption to the participant, retention of the comfort of the participant's natural surroundings, and ensure safety in the context of COVID-19 for both participant and researcher.

Practical guidance from the literature indicated the benefit of making an introductory contact first for preliminary rapport building to establish trust and encourage open disclosure during the interview (Dempsey et al., 2016), and which was carried out with all participants when discussing and arranging the interview. Due to the lengthy conversation required to explain the interview and consent process, this first contact allowed the author to separate the explanatory conversation from the interview. This was valuable procedure for the author to undertake as it ensured that participants' energy levels were not depleted by rapport building and the explanation of the research before the interview. The author employed both this introductory rapport building contact and an introductory script to reintroduce the study at the beginning of the interview, intended to enhance participant trust in the author, comfort the participant within the interview setting, and promote participant open communication.

Conducting phone interviews with participants had a number of distinct benefits and which are supported by the literature. The lack of non-verbal cues associated with phone interviews meant that everything had to be articulated clearly by the interviewer to the research participants (Holt, 2010). Participants also checked for clarification from the author in terms of whether their response was sufficiently long or detailed enough allowing the author to prompt participants further in the interview. The author found that through expressions in tone and extensive articulation of participants' thoughts, phone interviews were as rich in detail as transcripts generated from in-person interviews. The author also found that phone interviews were on average as long as the in-person interviews conducted in the study which is concurrent with previous research utilising both phone and in-person interviews (Lechuga, 2012; Ward et al., 2015).

3.11.4 Relationship between the interviewer and participants

Rapport building between the author was essential to gain the depth in the data required for the study, and arguably for qualitative research in general (Gysels et al., 2008; Wood et al., 2019). The ability of the author to build a rapport with participants was essential to capture relevant data in the interviews. The author treated all participants with the sensitivity required to carry out research of this nature and with the degree of empathy and observational skills required for the research. Importantly, a trusting rapport between the author and the participants fostered open communication with participants.

3.11.5 Participant member checking

Member checking is a qualitative validation technique whereby the researcher checks the accuracy of data with participants (Birt et al., 2016). This validation technique can be gained by both written or verbal means, with the researcher returning the transcript to the participant for review and/or by confirming and verifying meaning and asking for clarity during the interview. The author opted to undertake both forms of member checking as early interviews showed some participants' reluctance to read and review their transcript given the possibility that reading the transcript might cause upset to them. Due to the potential for deterioration of the patient's condition, interviews were ordinarily transcribed within 24 hours of interview so that they could be returned to participants in a timely manner. The sensitive content of the transcripts and disclosure meant that some participants declined to have their transcript returned to them (n=4). Member checking was also conducted during the interview. All participants in the study confirmed their intended meaning through conversational summarisation of the interview at the end of the interview. Overall, both strategies for participant member checking as mentioned had the ability to clarify and correct what participants expressed in the interview. No participants requested alteration to their transcript (i.e., data). The use of both within-interview and post-interview member checking contributed to the confirmability, dependability, and credibility of the study.

3.12 Data analysis

The data were analysed as per grounded theory coding procedures (Corbin & Strauss, 2015). First, the data were open coded which involved breaking down the transcript data into codes and concepts (aggregation of similar codes) that captured key incidents, events, and patterns that tentatively pointed to mutual support between patients and caregivers including barriers and/or facilitators to supportive relationships between them. Here, the second form of memoing was undertaken by the author. As analysis progressed, concepts had become clarified and segments of data that were illustrative of these concepts were highlighted through memoing. This allowed the author to see connections between data. A sample of a memo compiled during data analysis is available in Appendix L.

Data were then coded to achieve 'conceptual saturation' which involved expanding the concepts identified by building relationships between concepts and accounting for actions/interactions and/or behaviours in similar and different contexts. In grounded theory, this stage of coding is referred to as axial coding. For example, in the early to mid-stage of data collection, few patients and family caregivers reported dissatisfaction with each other. At this point, 'obligation' had emerged as a category which constituted feeling a need to support one another but also in some cases, family caregivers feeling constrained by having little choice but to support their ill family member. The author then sampled some participants, within the inclusion criteria, where there was already known tension in their relationship, as advised by gatekeepers, to better account for how obligation functioned between patients and family caregivers.

The final stage of analysis involved 'theoretical integration' of the data to fully identify processes of mutual support between the patient and family caregiver and the factors that hindered and/or facilitated mutual support between them. For example, the author identified that patients' desire to provide emotional support was motivated in part by the loss of other forms of support they felt able to provide. Family caregivers had already reported feeling responsible for the patient and for many family caregivers, responsible care included being of emotional support to the patient. The

author then probed and prompted both patients and family caregivers as to why reciprocation of emotional support was of benefit to both the patient and caregiver. The analysis of the data revealed that mutual emotional support was necessary for patients and family caregivers to better understand each other's viewpoint and balance each other's needs against their own. Rigour in the analysis was enhanced through peer debriefing between the author and the author's PhD supervisor. NVivo12 qualitative data analysis software was used as a tool to organise and code the data.

3.13 Description of participants

In summary, the participants were 15 patients (n=14 cancer, n=1 neurodegenerative disease) and 21 family caregivers (total n=36). Tables 2, 3, 4 and 5 (pgs. 70, 72-73) are modified versions of tables already published from the study (please see Appendix A) and they provide a detailed summary of participants. Participants in Tables 2, 4 and 5 have the unique participant ID code, with 'FCG' indicating family caregiver and 'P' indicating patient; shared numeric identifiers indicate a patient-caregiver dyad except for P15 and FCG15 who were non-dyad participants. Data extracts in the findings chapters of the thesis are also tagged using the ID code system.

Table 2. Outline of participants*

	Relationship to FCG/P	Dyad/non-dyad	Diagnosis of patient participant/patient cared for	Care setting †	Urban/suburban/non-urban
P1	Wife	Dyad	Stage IV breast cancer	SCPC	Suburban
FCG1	Husband			SCPC	Suburban
P2	Husband	Dyad	Progressive multiple sclerosis	Inpatient	Suburban
FCG2	Wife			Inpatient	Suburban
P3	Partner	Dyad	Stage IV lung cancer	SCPC	Suburban
FCG3	Partner			SCPC	Suburban
P4	Mother	Dyad	Stage IV Hodgkin's lymphoma	SCPC	Suburban
FCG4	Daughter			SCPC	Suburban
P5	Husband	Dyad	Stage IV pancreatic cancer	SCPC	Suburban
FCG5	Wife			SCPC	Suburban
P6	Mother	Dyad	Stage IV lung cancer	SCPC	Suburban
FCG6	Daughter			SCPC	Suburban
P7	Father	Dyad	Stage IV liver cancer	SCPC	Suburban
FCG7	Daughter			SCPC	Suburban
P8	Husband	Dyad	Stage IV lung cancer	SCPC	Suburban
FCG8	Wife			SCPC	Suburban
P9	Father	Dyad	Stage IV stomach cancer	SCPC	Urban
FCG9	Daughter			SCPC	Urban
P10	Husband	Dyad	Stage III prostate cancer	SCPC	Suburban
FCG10	Wife			SCPC	Suburban
P11	Wife	Dyad	Stage IV breast cancer	Inpatient	Urban
FCG11	Husband			Inpatient	Suburban
P12	Husband	Dyad	Stage IV lung cancer	SCPC	Suburban
FCG12	Wife			SCPC	Suburban
P13	Husband	Dyad	Stage IV colorectal cancer	SCPC	Suburban
FCG13	Wife			SCPC	Suburban
P14	Father	Dyad	Stage III colorectal cancer	SCPC	Suburban
FCG14	Daughter			SCPC	Non-urban
P15	Husband	Non-dyad	Stage IV lung cancer	SCPC	Suburban
FCG15	Daughter	Non-dyad	Stage III ovarian cancer	SCPC	Suburban
FCG16	Daughter	Non-dyad	Stage III lung cancer	SCPC	Suburban
FCG17	Husband	Non-dyad	Stage IV lung cancer	SCPC	Urban
FCG18	Daughter	Non-dyad	Cardiac failure	SCPC	Suburban
FCG19	Daughter	Non-dyad	Stage III lung cancer	Outpatie	Suburban
FCG20	Daughter	Non-dyad	Stage III colorectal cancer	SCPC	Suburban
FCG21	Son	Non-dyad	Advanced bone cancer	SCPC	Suburban

*Reproduced from McCauley et al. (2023c) †SCPC = specialist community palliative care

The sample comprised 14 patient-family caregiver dyads, seven family caregivers who participated as non-dyad participants, and one patient who also participated without their respective other. Family caregivers participated on their own when the patient's health status deteriorated between the author's initial approach and the scheduling of interviews to the point that the patient felt too unwell to participate. For the one patient who participated without their family caregiver, the family caregiver had declined to participate because of her own distress. The majority of patients were men (11 of 15), and the majority of family caregivers were women (17 of 21). The average age of women patients was 58 years, and the average age of men patients was 67.5 years. The average age of women caregivers was 51.5 years, and the average age of men caregivers was 57 years. The sample was primarily suburban based. Most patient participants had metastatic cancer (i.e., stage IV). Thirty-one of the 36 participants were recruited via the community (i.e., home-based) specialist palliative care service as other locations at point of recruitment (e.g., outpatient and day hospice services) were affected by periods of COVID-19 restrictions. The remainder of participants were recruited through inpatient and outpatient hospice.

The majority of the 15 patient participants (n=9) had already ceased full, active treatment (e.g., radiation therapy, chemotherapy). No participating patient or non-participating patient of a participating family caregiver in the study had a prognosis of >18 months.

3.14 Description of the dataset (interviews)

The 15 patients and 21 family caregivers participated in 30 qualitative interviews as outlined in Table 5 (p. 73). Interviews were conducted with eight of 14 patient-family caregiver dyads separately, with each member of the dyad interviewed on their own (16 interviews), and six dyads requested that they be interviewed together, with both patient and family caregiver in one interview (six interviews). The seven family caregivers and the patient who participated without their respective other were each interviewed alone. Twenty-seven of the 30 interviews were conducted remotely: 25 by phone and the remaining two by the video-conferencing platform Zoom (Version

5.3.1), through which all meetings were secured with end-to-end encryption. The average duration of interviews was 43 minutes.

Table 3. *Participant gender and age profile**

Gender	No. of participants (n=36)	% of total participants	Age range
Men patients	11	30.6%	46 – 90 years
Women patients	4	11.1%	40 – 77 years
Men caregivers	4	11.1%	43 – 70 years
Women caregivers	17	47.2%	22 – 80 years

Table 4. *Breakdown (including %) of patients and caregivers**

FCG relation to patient	(n=21)	FCG participants
Spouse/partner of patient	10	47.6%
Adult child of patient	11	52.4%
Patient relation to FCG	(n=15)	Patient participants
Spouse/partner of caregiver	10	66.6%
Parent of caregiver	5	33.4%
	(n=36)	

Table 5. Mode of interviews for data collection*

P/FCG	Interviewed together / alone	Mode of interview
P1	Together	Zoom audio & video
FCG1	Together	Zoom audio & video
P2	Together	Phone
FCG2	Together	Phone
P3	Alone	Phone
FCG3	Alone	Phone
P4	Alone	Phone
FCG4	Alone	Phone
P5	Alone	Phone
FCG5	Alone	Phone
P6	Together	Phone
FCG6	Together	Phone
P7	Alone	Phone
FCG7	Alone	Phone
P8	Alone	In person
FCG8	Alone	In person
P9	Together	In person
FCG9	Together	In person
P10	Together	Phone
FCG10	Together	Phone
P11	Alone	Phone
FCG11	Alone	Zoom audio & video
P12	Together	Phone
FCG12	Together	Phone
P13	Alone	Phone
FCG13	Alone	Phone
P14	Alone	Phone
FCG14	Alone	Phone
P15	Alone	Phone
FCG15	Alone	Phone
FCG16	Alone	Phone
FCG17	Alone	Phone
FCG18	Alone	Phone
FCG19	Alone	Phone
FCG20	Alone	Phone
FCG21	Alone	Phone
	Total = 30 interviews	

*Published in McCauley et al. (2023c)

All patient participants were in their recruitment site (i.e., at home or as an inpatient) when interviewed. All family caregivers were interviewed whilst they were in their home, bar one family caregiver who was interviewed in the patient's inpatient care setting. A sample interview transcript can be found in Appendix M.

3.15 Strengths and limitations of study procedures

The study's procedures have both strengths and limitations. Despite the difficulties imposed by COVID-19, the author managed to recruit both patients with advanced illness and family caregivers for a qualitative study in palliative care where the focus was on relations between patients and family caregivers. However, recruitment was limited to one regional-based hospice service and in the end, largely to specialist community palliative care. The findings as reported in the next three chapters, are therefore highly contextualised to participants' experiences in specialist community palliative care. The study did not manage to capture variation in patient diagnoses ordinarily seen in palliative care and so the findings are also contextualised primarily to palliative care in cancer.

In Ireland, there has been a tradition of family-based decision making in palliative care, but also in more recent decades, reduced societal expectations that family be involved in decision making or indeed provide support and care. Hence, the findings are representative of the social and cultural context in which participants of the study participated. Nonetheless, the author has described the setting, procedures, and participants in detail to enable transferability of the findings to similar and different contexts (Lincoln & Guba, 1985). Although the findings presented in chapters four, five, and six are not generalisable (in quantitative terms) to the wider population of patients with advanced illness and family caregivers in palliative care, they do allow for comparison across both similar and different contexts which is a key aim of qualitative research. As already described, data were member checked and then examined between the author and the author's PhD supervisor as strategies to promote dependability and credibility of the findings, approximate equivalents to 'reliability' and 'validity' in quantitative design (Lincoln & Guba, 1985). In addition, memos were

formulated by the author at key stages of the analysis which together with coding, comprised an audit trail of the analysis.

Of note, the study did not capture change in either patients' or family caregivers' status given that data collection occurred at one point in time for each participant. However, the study was not designed at the outset to be a longitudinal study of mutual support between patients and family caregivers in palliative care given the scope of the PhD study and the challenges of conducting longitudinal qualitative research with people who have both severe and advanced illness. Whilst many family caregivers reported high levels of carer burden, family caregivers were not asked to formally rate the intensity of their caregiving. However, the burden reported by caregivers is found in and contextualised across the data. Family caregivers' perceptions surrounding the intensity of their caregiving impact on how they provide support to their ill family member and how they engage in decision-making for treatment and care.

A small proportion of the sample (n=8) did not participate as dyads. Hence, in these cases, it is possible that their data generated were less contextualised to their respective other when compared to participants who participated in the study as dyads. However, of key importance is the fact that the sampling and analytical procedures used allowed for constant comparison of data across the dataset, not limited only to comparison within, between or across dyads. Regarding data collection specifically, the initial protocol for conducting interviews was that they would be conducted in-person. However, the author was required to adjust procedures to facilitate remote interviewing because restrictions imposed by COVID-19 reduced the possibility in most cases for in-person interviews. Many of the participants who agreed to participate in the study did not have technological literacy in using General Data Protection (GDPR) compliant platforms (e.g., Zoom, Teams) and were not able to engage with these platforms as a mode for interview. Hence, as already outlined in this chapter, most interviews with participants (25 of 30) were conducted by phone. Phone interviews in qualitative research can be as productive as face-to-face interviews (Holt, 2010; Novick, 2008; Sturges & Hanrahan, 2004) and were found by the author to be an effective mode of data collection in this study. Nevertheless, more in-person or video-based online interviews would have allowed for observation of participants in

interviews (Foley, 2021) which might have resulted in capturing and/or contextualising even further the depth of emotion conveyed by participants in their interviews.

As detailed, the majority of patient participants in the study were men (11 of 15), and the majority of family caregiver participants in the study were women (17 of 21). As is common in palliative care research, it proved more difficult to recruit family caregivers who were men (Gott et al., 2020). A greater presentation of men family caregivers in the sample would have enabled the author to capture more detail on dimensions of caregiving from the perspective of men and how differences between men and women as caregivers can impact on decision-making in palliative care. Lastly, the study protocol did not include formal neuropsychological testing, or any other form of formal cognitive or psychological testing, of patient participants. Any patient who had participated was deemed by gatekeepers and by their medical team to be able to partake in a qualitative interview. Such data could have served to further contextualise the interview data.

Overall, the quality of the study's findings is judged by a number of criteria: fit, concepts, contextualisation, logic, depth, variation, applicability, and sensitivity (Corbin & Strauss, 2015). As outlined above, member checking was conducted to ensure that the findings resonated/fitted with the experience of those who participated in the study. Concepts were generated and expanded to explain the data. Participants' experiences were then contextualised to understand how concepts related to each other and to make comparisons between data. The procedures undertaken by the author have been reported logically in the thesis. The findings reported in the next three chapters are dense in description and incorporate variation in meaning to capture the complexity of relationships between the patient and family caregiver in palliative care. The findings have applicability to practice and policy in palliative care because they offer much needed evidence on relational decision-making between patients and family caregivers in palliative care needed to support both patients and family caregivers. Finally, the author has been sensitive to the topic under study and reflexive throughout the research. In short, the study adheres to and meets criteria for quality grounded theory qualitative research.

3.16 Chapter conclusion

The present study is novel because research to date lacks the explanatory detail on mutual support between patients and family caregivers in palliative care. The findings of the study are presented next in chapters four, five and six of the thesis. While the findings of the study are not generalisable in quantitative terms to all patients and their family caregivers in palliative care, they are grounded in real-world life experiences of patients and family caregivers in palliative care. Identifying key processes of mutual support between patients and family caregivers, the factors that facilitate and/or hinder supportive relationships them, and how patient and family caregiver mutual support impacts on their decision-making for treatment and care can help identify strategies and aid the development of interventions focused on enabling and facilitating supportive relationships between patients and family caregivers including when they are faced with making decisions about treatment and care.

Chapter 4: Processes of Mutual Support between Patients and Family Caregivers

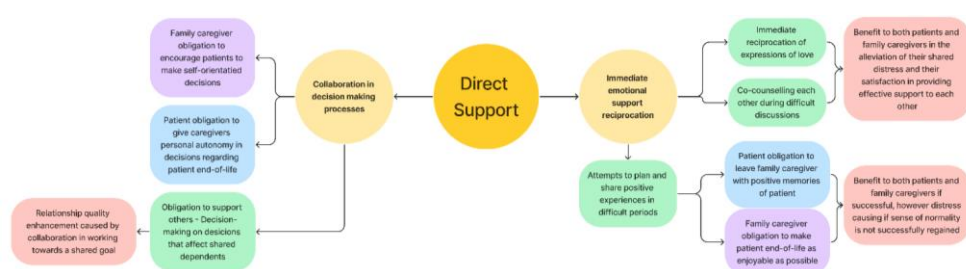
Chapter 4: Processes of mutual support between patients and family caregivers

The reciprocation of support between patients and family caregivers took, primarily, two forms. First, support was reciprocated in the same way and often in tandem by the patient and family caregiver, referred hereto as direct mutual support. Second, support was exchanged indirectly, whereby patients could not reciprocate the same type of support given to them by family caregivers and they resorted to reciprocating by rendering a different type of support to the family caregiver which they still had the capacity to provide. This chapter outlines these two forms of support exchange (direct mutual support and indirect mutual support), the contexts in which these forms of support were provided and received, the motivations behind providing support to one another, and the effects of different types of support on the recipient of the support. All names of participants mentioned in this chapter and in the following findings chapters are pseudonyms. Any other people mentioned by participants in their interviews have also been pseudonymised.

4.1 Direct mutual support

Direct mutual support occurred when both the patient and family caregiver were able to provide the same type of support to one another. Direct mutual support involved primarily the exchange of psychological and emotional support and was often rendered by patients and family caregivers in tandem. Sections 4.1.1 to 4.1.6.5 inclusive explain how direct mutual support functioned between patients and family caregivers. Examples of direct mutual support are illustrated in figure 3 below.

Figure 3. *Examples of direct mutual support*



4.1.1 Mutual disclosure

Both patients and family caregivers reported the benefits of open emotional disclosure in interactions with each other. Mutual openness allowed for intuitive support, with patients and family caregivers intuiting the needs of their counterpart without the necessity for prompts or questioning. Patients and family caregivers who typically disclosed openly to one another created a more acute degree of awareness amongst them, by which they could measure the feelings of one another by the degree to which their counterpart opened up or closed off:

[My daughters] can tell if there's something wrong with me... they could tell right away... Sometimes too, Isabella [daughter, primary family caregiver] would go quiet and there do be things on her mind. So we just talk about it. I try to just put her straight or just put her mind at ease and everything like that.
(Neil, P7)

Open disclosure therefore acted as both a support form whereby both parties could transparently communicate, and a barometer for measuring the wellbeing of one another. Mutual disclosure allowed for deeper understanding of one another's perspective and could allow patients and family caregivers to create a shared viewpoint of their circumstances and enabled them to cope collectively:

You know, like we've, we [patient and family caregiver] say we're singing from the same hymn sheet and we're pretty I think understanding of one another, and the way each other handles things and copes with things. So, I think as I say, it's just because we know each other so well. We're lucky that way. (Mick, P3)

The degree to which disclosure between patients and family caregivers was open before the patient's diagnosis appeared to be influential on the openness of their disclosure within their newly assumed patient and caregiver roles. This continued type of support allowed for both alleviation of the family caregiver's distress and empowerment of the patient in offering a caregiving role. These benefits were in

addition to the retention of a sense of normality, with the patient and family caregiver having the ability to carry out roles held pre-morbidity, albeit in a reduced capacity:

It's funny... even, as I said, in our situation, I still look to her [patient] for things you know. What do you think of this or what do you think of that, you know. So yes absolutely... like she's still with me albeit in a reduced way, and I think it has made us a lot closer too. But absolutely she can be support, for sure. (Eamonn, FCG1)

4.1.2 Expressing affection and positive emotions to one another

In addition to sharing with each other their own distress, the sharing of positive emotions was prevalent among patients and family caregivers though expressions of love and affection for one another:

She [patient] can't say enough 'What would I do without you?' and 'I'd be lost without you' and eh, then I tell her I love her an awful lot, and she registers... that registers with her, 'I love you as well' kind of thing. (Seamus, FCG17)

Patients and family caregivers often reported the purposive effort to de-escalate each other's distress through reassurance, encouragement, and positively focused conversation. Patients and family caregivers also attempted to both dwell on positive memories and to make new positive memories. For example, patients and family caregivers attempted to do enjoyable activities together whenever the patient reported feeling well enough including going on holidays, to restaurants, or sharing scenic walks:

We [patient and family caregiver] can go to the park and get out and walk a short distance or something ... the energy in the legs is getting a bit worse every day. The walks are getting shorter on me but they're fine with it... we still find places where we go and sit and talk. (Frank, P5)

When patients were unable to take part in activities outside the home due to both symptom severity and COVID-19 risk and restrictions, the development of positive memories was also prioritised by patients and family caregivers. Patients and family

caregivers along with other family members made considerable efforts in organising uplifting activities such as sing songs, playing games, and having parties:

We're always joking and messing, you know? ... Well, we sing together and have a laugh and play cards and things like that, where we never talk about cancer. (Louise, P6)

4.1.3 Maintaining normality for one another

While new opportunities for positive experiences were introduced by many participants, other participants also wished to nurture their pre-existing relationships by insisting on the retention of their previous rituals. Indeed, many patients and family caregivers reported the positive effects of the retention of normalcy within their day-to-day lives. While some patients reported being infantilised by others, a significant contributor to the retention of their dignity was the maintenance of some of their normal daily processes and roles:

Could just be the smallest things, you might have a coffee somewhere and just chat and then, you know, it's nearly like we made that promise to ourselves. (Irene, P1)

While stating that the preservation of normality was intended for the patient's benefit, it could also be advantageous for family caregivers who were appreciative of a semblance of their previous lifestyle after their lives had profoundly changed following the patient's diagnosis. As well as contributing to their family caregiver's sense of wellbeing, projecting an image of normality also satisfied their need to protect others from the reality of the situation at hand:

Trying to be as normal... as normal as you were before ... going for walks or going out for a meal, or the usual things that we would have done before he got the diagnosis kind of thing, you know. Yeah, definitely like, for the kids as well, like, to see that we're still the same as such. (Anna, FCG5)

4.1.4 Making decisions now and for the future

Conversations regarding treatment decisions were generally patient-focused. However, decisions about the future, particularly decisions which could affect the life of shared dependents and the family caregiver's life after the patient had died, were made in accordance with the needs and wants of family caregivers and shared dependents in addition to the patient's preferences. In this context, decisions about the future were generally made by the patient and family caregiver with the wider family in mind. Hence as outlined in sections 4.1.4.1 to 4.1.4.3, mutual support between patients and family caregivers manifested both in the decision-making process on matters relating to family in addition to the decision-making process pertaining to the patient's treatment and care.

4.1.4.1 Maintaining shared caregiving of others

When attempting to make decisions for the future, the utmost priority for patients and family caregivers with shared dependents was the safeguarding of wellbeing and preparation for the future of their shared dependents. Patients and family caregivers shared the opinion that their shared dependents would be prioritised both while the patient was receiving palliative care and after the patient had died. As a result of this prioritisation, patients and family caregivers reported that stress arose for them around concerns in their caregiving roles for their children and shared dependants. This particularly occurred for patients and family caregivers attempting to retain their caregiving role for their dependents while also experiencing a change in roles with their counterpart and a significant lifestyle change as a result of the patient's illness:

Obviously, you know, it's, we're a two person team as well, you know, and certainly for me, and I suppose my understanding of the situation as well, it's, it's very, very important to me to kind of be hands on, because I need to know what's going on with Irene [patient], but we have to live our lives together as well apart from the, you know, Irene's condition, and that's incredibly important too, and for our daughter as well. (Eamonn, FCG1)

Patients' and family caregivers' collective concern about their shared dependants was prevalent regardless of whether those dependants were living in the family home or had families and homes of their own:

I feel very, very sorry for the girls [adult children]. Like I feel sorry for myself, but I'm much older. And I just think it must be very difficult for them to see their dad like this. And the three of them have young babies. (Tina, FCG8)

4.1.4.2 Making life-prolonging decisions

Patients and family caregivers supported each other in decision-making on aspects of care that triggered communication around issues pertaining to length of life and quality of life. The way in which each acted within this process was linked to the outcome they thought their respective other would want from the conversation. In some cases, family caregivers' assumption of patient stoicism led family caregivers to assume that the patient would endure significant pain to please family caregivers:

I know he wants to spend as much time with us as possible and I do feel that same way. But like, at what cost as well? So I just don't want to see him in pain basically. (Isabella, FCG7)

Conversely, the patient's attempt to predict the family caregiver's wishes manifested in the patient assuming their family caregiver, and in many cases the wider family, would prioritise additional time over all else:

Any chance at you know, even an extra day, I was going to grab it with both hands... I felt responsibility that I had to do this for them, if not for myself, for them. (Irene, P1)

Of note, regardless of the degree of openness of disclosure, some patients and their family caregivers appeared to still misunderstand each other's wishes or assume that the other member's stoicism concealed their true wishes:

I know if anything goes wrong... that's why I let Pauline [family caregiver] know when she's at home in her own place [that I am okay], just one call and she'll be

over. I want her to get some of her own life together and not mine all the time.
(Tom, P14)

Only recently, I spoke to family members, as in my spouse and things like that, to say that I would rather Dad [patient] pass quicker and keep his dignity than linger on, and he [Dad] doesn't like being dependent [on me]. (Pauline, FCG14)

Overall, attempting to find the balance between retaining quality of life and sustaining life was at the centre of most patient and family caregiver decisions. Patient and family caregiver obligation to each other and in particular their attempts to intuit and uphold each other's wishes in these discussions was a key feature of their communication when making decisions about care.

4.1.4.3 Preparing for the patient's death

Due to the patient's fragile health condition and potential for rapid deterioration, preparedness for death was a priority for family caregivers. Patients supported family caregivers by assisting them in the preparation for their own death while family caregivers provided support to patients by ensuring their end-of-life wishes were heard and honoured:

When I was diagnosed we sat down, and I had to make arrangements in the long... in the long term, you know, like, as I say, funeral arrangements, what I wanted and everything... and [so] we sat down, and we discussed what I wanted. (Neil, P7)

As with many of the codes in the present section (4.1.4), this code was not discussed in great detail within the interviews, the regularity of its occurrence within almost all interviews justified its inclusion within the present study. While patients and family caregivers did not describe the actions they were taking to prepare for the patient's death, potentially due to those plans being in their early stages, their recurrent mentioning of this imminent process indicated that they were preparing one another for these plans to be laid in the near future.

4.1.5 Adapting to a different life

In addition to the preparation for the future, patients and family caregivers also had to adapt to a different reality. Their collective adjustment to a new routine that was regularly disrupted by the patient's changeable illness was a difficult change, particularly for those patients and family caregivers that had previously had a well-practiced, habitual daily routine in place for a long period preceding the patient's illness. Patients reported obvious change in their daily roles:

I would have always held the house down, did the washing, the cooking, the cleaning the shopping, and I would have always done all that. And that has changed drastically. I don't do any of that anymore. I've been told I can't lift anything heavier than a kettle. And so, you know, with regards to doing hoovering or something like that's a huge, huge task for me and one that I'm just frankly not able to do, so Eamonn's role and my daughter's role as well ... they've taken on that role that that was mine. (Irene, P1)

In attempting to adapt to a different life, patients and family caregivers exchanged roles and took up new roles to address the discrepancy in responsibilities created by the patient's inability to fulfil their previously held roles. Patients' loss of physical energy made their effortful responsibilities difficult to complete. Family caregivers often adopted these roles while patients took up new roles which included for example, providing emotional support and encouragement to their family caregiver. Sections 4.1.5.1 to 4.1.5.4 outline the different dimensions to role change and/or retention of roles among patient and family caregiver participants in their effort to support one another.

4.1.5.1 Taking on new roles

Patients and family caregivers directly supported one another by both undertaking new roles and assisting one another in the assumption of these new roles. Patients and family caregivers that were exchanging roles were required to illustrate what their former roles consisted of in order for both parties to succeed in the uptake of their

new roles. In this way, both patients and family caregivers provided instruction based on historical behaviours, advice and support for one another negotiating their new roles. For instance, patients that formerly held caregiving roles assisted family caregivers in illustrating what their former caregiving roles consisted of, particularly with a view to caring for others. Family caregivers assumed new roles following the example set by the patients in the patients' pre-morbid caregiving roles:

I'm emotionally there for her [younger sister] as like an older figure... when my Dad doesn't have the energy to do so. I think I have more stuff around the house as well... I've been doing it more. (Isabella, FCG7)

Patients' new roles were mostly sedentary, with the family caregiver and other family members enforcing that the patient's only responsibility should be their own rest and recuperation. These new more passive roles for the patients caused in some cases, acute frustration for them particularly if the patient had active caregiving roles in their household before their illness:

I find it a bit frustrating. I'm saying 'Jesus, you know, she's enough to be doing to have to do that as well.' You know, when I was doing all the shopping and stuff like that, and now it's all turning on her [family caregiver]. (Mick, P3)

4.1.5.2 Retaining roles

While some roles were relinquished with relief by the patient, others were retained by patients due to their emotional value they attached to them. Of note, retaining certain roles were non-negotiable to the patient regardless of the amount of effort required to fulfil them. This was particularly the case for patients who still felt obliged to fulfil collective caregiving duties with their family caregiver to their shared dependants:

My son, when he has a fight with the girlfriend, that's the only time he ever opens up but other than that he'd tell you nothing. But he'd still come to me for advice about different things, like work or different things like. I help him that way. (Louise, P6)

A significant factor in the reduction of distress for both the patient and family caregiver was the ability to retain their roles of providing emotional support to each other regardless of degree of patient illness or their collective emotional distress. Family caregivers that still had the ability to rely on the patient for emotional support found comfort in doing so even if this was accompanied by feelings of guilt for potentially burdening the patient. The retention of this type of mutual support between patients and family caregivers was particularly important for participants who were spouses and who relied on each other for counsel:

She [patient] still gives so much you know. And I still look to her. And some people might say 'Oh that's not right... you know she's not well, he shouldn't be asking her this or that or whatever' but no that's what you do, that's what I'm doing in certain ways. (Brian, FCG11)

4.1.5.3 Maintaining roles

Ensuring that the family kept on top of their typical day-to-day tasks as normal was important to both family caregiver and patient. For a seamless transition to their new routines, patients and family caregivers often maintained supportive roles:

It's been a major change to our lives, but it hasn't changed our relationship in terms of, obviously, our love for one another and everything like that... I think overall, that's down to the two of us kind of being able to take responsibilities on and both for one another as well. So, you know, there's, like, there's something to be said, for doing all the bits and pieces that the day-to-day stuff but being there for one another is probably the most important part I think of how we're dealing with things at the moment. (Eamonn, FCG1)

Patients attempted small acts of care for the family caregiver when possible. While it was sometimes acknowledged by the patient that these acts were more tokenistic than of practically helpful, both patients and family caregivers stated the importance of the effort and intention behind these gestures of support over the actual effect of such support for one another:

I try and help out if I can, just the small things, like maybe lighting the fire or something. (Mick, P3)

Patients also sought to carry on with duties that assisted family caregivers in tasks that they would have undertaken together prior to the patient's illness and particularly if such tasks did not require physical exertion:

I'm still there on the financial side of things, we still sit down and that's still runs the way it was always run. We talk about that when we sit down, we budget, we still do all that. (Irene, P1)

4.1.5.4 Resisting and negotiating change in roles

Adjustment to a different or new role was a difficult process for both patients and family caregivers. Patients struggled with the loss of their ability to perform their previous roles especially if the role was a significant part of their identity, such as the sole driver of the household now being unable to drive or the breadwinner of the household now unable to earn money for their respective family caregiver and the wider family:

I don't do anything that I used to do. And it frustrates the hell out of me. (Irene, P1)

Some patients, particularly those who were a parent of an adult child who was functioning as their family caregiver, experienced difficulty adjusting to being a care recipient in the context of always having provided support to their family including their now family caregiver:

They're not looking after me if I became incontinent or paralysed or you know ... I wouldn't be able to cope even thinking about it. I'm nearly breaking out in a sweat like thinking about it, so no there's not a chance I'd let them look after me like that. (Louise, P6)

Indeed, adult children who had assumed family caregiver roles often struggled in convincing their parent to accept care and relinquish their perceived role as leading decision-maker in the family:

At the end of the day, I'm still only his kid. I'm still his daughter, now I can't overrule my father. I can't say 'Yeah you're going' because he'd say, 'Get out you', but it's his word at the end of the day. (Frances, FCG9)

4.1.6 Shared coping

In order to maintain a sense of normality and alleviate distress throughout their daily lives, patients and family caregivers created a shared coping style in which they both found relief. Coping styles manifested in shared patterns of actions and reactions in response to their shared stressors. Coping strategies employed by patients and family caregivers as explained in the next sections of 4.1.6.1 to 4.1.6.5 ranged depending on the personality traits of patients and family caregivers and the nature of the relationship between patients and family caregivers.

4.1.6.1 Shared humour

Patients and family caregivers sought to have humour in their interactions with one another. Shared humour was often dependent on the closeness of the relationship between one another prior to the patient's illness. All patient participants in the study displayed humour throughout their interviews and they also commented on the benefits they perceived that humour resulted in. Of note, many family caregivers were grateful for the patient to also invest humour into their relationship with them. Indeed, investment of humour by the patient provided respite from the heaviness of end-of-life focused discussions for both the patient and family caregiver:

Sometimes in the middle of things being really bad, he [patient] has like a wicked sense of humour. He will turn something into some into a thing that's absolutely hilarious. You can find yourself laughing in the middle of all that. (Tina, FCG8)

Humour was exchanged between patients and family caregivers once initiated by the patient. Family caregivers were aware that the patient was open to utilising humour as a coping mechanism that benefited both the patient and family caregiver. Existence of humour in the patient and family caregiver relationship before the patient's illness

allowed patients and family caregivers to utilise it to de-escalate distress for one another and to dissipate the seriousness of their shared circumstances:

[We would be] messing about stuff which we know is serious, but they try not to make it serious and they try to look on the bright side of life. (Neil, P7)

4.1.6.2 Concealing pain and emotional distress

Amid the efforts of attempting to remain positive for one another, patients and family caregivers also indicated that they concealed and/or under-reported their negative feelings from/to each other. Of note, patients and family caregivers who were spouses perceived themselves to be less able to convincingly conceal symptoms due to the closeness and intimacy of their relationship. However, patients whose adult child was their caregiver were more convinced of their ability to successfully hide their distress from one another. Regardless of the caregiving relationship between patients and family caregivers, patients frequently stated that they regularly under-reported both their physical pain and emotional distress so as not to increase family caregiver burden:

The more I look well, and I do my best to get dressed and look well every day, that's a thing that helps everything then you know? (Frank, P5)

However, family caregivers indicated that they under-reported or concealed their degree of burnout and distress:

Sometimes you look at her [patient] and like every day she's dying a little bit more and you kind of have to pull yourself because she'd be like 'Oh what's wrong? What are you looking at?' and you'd say, 'Oh nothing, nothing, it's fine' and she'd be like that 'Are you okay? Did something happen at home?' and you'd be like 'No, no it's fine' because you don't want to say, 'Well I'm looking at my mam passing away in front of my eyes', you can't say that to her. (Niamh, FCG20)

Of note, patients' ability to conceal pain and emotional distress could lessen with deterioration of their condition, breaking in some cases, the reciprocal exchange of this type of support between them and their family caregiver:

I'd always be the one to put up 'Oh I'm fine!', I'd always put a front on... But then lately I don't... I can't do it anymore. Physically don't have the energy to hide it anymore. (Louise, P6)

4.1.6.3 Creating a shared perspective

Despite the patient being acutely ill and requiring care, the patient and family caregiver still created a shared perspective. Creating a shared perspective was contextual to the patient being at home and the comradery between patients and family caregivers was facilitated by both living together in their home:

That's a very important point about two people in a home that aren't able to do all the things they did before. The effort of the two of us is far greater and it helps, you know, really, that's a very strong point... It's a great relief to know that we'll manage this together. (Maggie, FCG10)

Creating a shared perspective was the result in many cases to relieve otherwise isolated experiences of grief and distress for both the patient and family caregiver. An important factor which participants felt contributed to the alleviation of mutual grief and distress was their ability to gain understanding and meaning from creating a shared perspective with their respective other. Creating a shared perspective was a prevalent feature of the dyadic relationship, with many patients and family caregiver reporting having reached consensus on how they would navigate palliative care together. This gave both focus and drive towards their shared goal, whether that be maintenance of normality, creation of positivity, or mutual disclosure:

This kind of change in our lives, if anything, it's given us a bigger focus on, maybe the smaller things that we mightn't have paid as much attention to as before. (Eamonn, FCG1)

Creating a shared perspective was a feature of relationships between patients and family caregivers who had reported positive and shared coping strategies and who bonded closely with their respective other through the experience of living with ill-health and having to engage with palliative care services:

Things haven't changed, although he's physically changing, like, health wise, deteriorating, like, nothing has changed, obviously, between myself and my dad. I think we're closer now than we ever were. (Jen, FCG13)

4.1.6.4 Remaining optimistic for one another and the wider family

Most patients and family caregivers expressed the importance of a shared positive attitude and they attempted to remain optimistic to raise the spirits of their respective other and of the wider family:

With the cancer you need to be so positive. And that's one thing I have to say is I'm very positive, and I will stay positive, that's one thing I know, especially for my family. (James, P8)

I'll just get on with it and just live a normal life. And that's what got me through it. Instead, I'd listen to somebody else's problems, and I'd end up helping them and I'd be worrying about them. And I take that on because that's who I am, I'd end up be going and helping them... So my motto was, just get on, just enjoy my family, and just get up and get on with it. And that's what kept me so strong. (Louise, P6)

You really have to stay on the positive. That's what I find. That's what I try and live by. It's not always easy, but it's the only way to go is to be positive. (Maggie, FCG10)

Patients held a primary role in setting the shared view, with family caregivers attempting to concur with the attitude the patient held regarding their illness and its progression. Patients acknowledged that the attitude they held would set the perspective for the other members of their family, and as such, they attempted to be as positive as possible to rally other family members to support their family caregiver:

I know there's some families where it can cause clashes and problems and, you know, people believe in different beliefs, and if you haven't got a positive attitude, you've got a negative attitude and it's going to rub off on the next person you know? So, we [wider family] try to keep the positive attitude as much as possible [for family caregiver]. (Frank, P5)

Family caregivers were often able to see through the patient's positive exterior and attempted concealment of pain. However, they chose to allow the patient to present this outward image to maintain positivity and normality within the household. Whilst family caregivers continued to offer support to the patient regardless of the patient's insistence of wellbeing, they were also grateful to accept the respite that manifested from the patient's stoicism:

She doesn't complain, she never complains! I don't know whether she'd be thinking of me... I think she probably holds things in at times and she doesn't really talk about it much. I'm always asking her are you okay and she'll say 'yeah, I'm okay', like she never complains. We're blessed with her like she's an angel. (Maria, FCG15)

4.1.6.5 Maintaining realistic expectations

Holding a shared realistic view based on healthcare providers' prognoses assisted patients and family caregivers in being prepared for illness advancement and the potential for sudden deterioration of the patient's condition. The shared perception of the reality of the situation enabled shared coping:

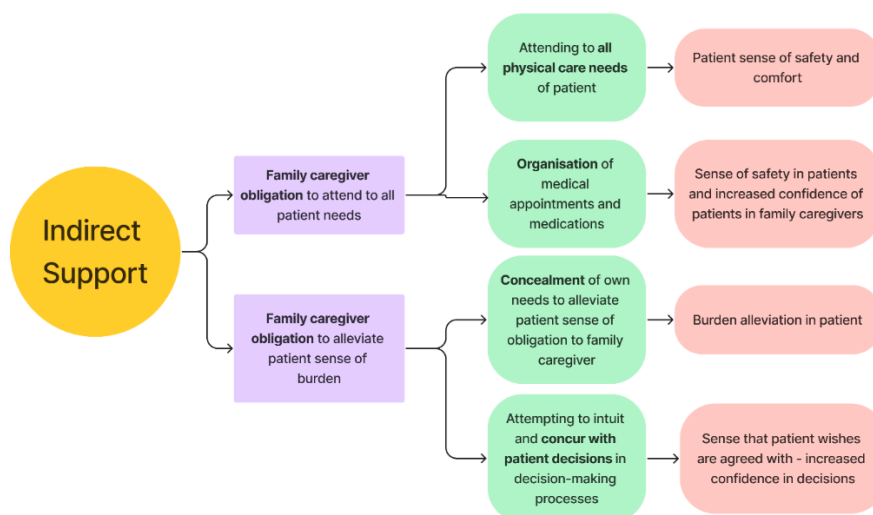
We, we both would be very realistic and would be very straight talking. So, we don't beat around the bush, when there's something wrong, we talk about it openly. (Pauline, FCG14)

4.2 Indirect mutual support

The provision of support was also reciprocated by patients in different ways than it was received. Patients found that certain types of support in certain contexts were outside of their remit for reciprocation due to their illness and medical treatments (e.g., assistance with housework, providing financial support, and even provision of emotional support due to their fatigue and severity of illness. Family caregivers felt obliged not only to support patients in their physical, emotional, and organisational needs, but also to constantly monitoring their respective other's increasing needs over time. Examples of family caregiver indirect support are illustrated in figure 4 below.

Patients themselves were generally motivated by wanting to ensure that their family caregiver retained elements of their pre-caregiving lives and did so by emotionally supporting their family caregiver where possible and by attempting to conceal as much of their discomfort and pain as possible to alleviate the burden on their family caregiver.

Figure 4. Examples of family caregiver indirect support to patient



Section 4.2.1 outlines in more detail why specific supportive behaviours could not be reciprocated by patients. The proceeding sections of 4.2.2.1 to 4.2.2.8 then explain types of supportive behaviours from the family caregiver that were in many cases, not feasible for the patient to reciprocate. Finally, sections 4.3 to 4.3.6 outline how patient participants still felt they were able to provide support albeit through different types of actions and behaviours.

4.2.1 Inability of patient to reciprocate in the provision of support

Patients at more advanced stages of illness were unable to provide the same degree of support they could offer at early stages of their illness. They reported an inability to provide any physical support or listen to the problems of others including their due to their limited energy levels, nor could they continue to conceal acute pain or emotional distress:

If I'm talking too long, that's also another big problem. It kind of drains me, takes away all my energy. When I have someone coming to the house and you're listening to their problems, they have their own problems. You know, mostly when people talk to you, they say you know 'How are you?', 'How do you feel?' and you say, 'Ah I'm grand' or 'I'm not great' and next thing you're listening to all their problems, and you sit there for a half an hour listening to their problems. And then they won't even let you get a word in. (Stephen, P15)

Patients regardless of the different stages of their palliative care interventions, experienced reduction in their ability to perform physical tasks, including their ability to drive, work, and household chores. At further stages of illness, patients were also unable to physically support themselves in terms of their personal care. Their frustration at being unable to perform physical tasks to support family caregivers were further exacerbated by having to also accept physical help from family caregivers:

At the moment, I suppose I'm more of a bloody hinderance than a support.
(Mick, P3)

4.2.2 Unreciprocated family caregiver support

A significant amount of family caregiver support could go unreciprocated by patients. This was generally anticipated by family caregivers who were happy to accept small attempts at reciprocation as reward for their efforts. Indeed, in some cases, patients who attempted to provide support through physical means distressed family caregivers. In many cases, it was impossible or unnecessary for patients to reciprocate support in the same way.

4.2.2.1 Offering security by being physically present

Both patients and family caregivers deemed the presence of a family caregiver helpful when engaging with palliative care services. Indeed, family caregivers, whether supported by secondary family caregivers or not, found it distressing to be away from the patient even if the patient was receiving formal care:

I do need the break but when I'm gone, I do just feel Oh god, I want to be back with her, I feel safer being in there with her to be honest with you. I do worry if anything happens and I'm not here with no one to take care of her so I'm a bit reliant on being here now, as she is having me here, so that can be difficult.

(Sarah, FCG4)

Patients found solace in knowing that they had a constant source of support whether it be for their emotional or physical needs. It was often the case that patients found the most benefit from the family caregiver in situations where the family caregiver simply engaged in conversation with them to distract themselves from their own distress and pain throughout the day:

She'd [family caregiver] be talking to me all the time so that's half the battle, just conversation, you know. So because there's nothing as bad as being stuck up here [upstairs] on your own. (Anthony, P13)

4.2.2.2 'Being there' in healthcare meetings

Family caregiver physical presence was also important to patients for healthcare meetings. Patients highlighted accompaniment to healthcare appointments as one of the most significant and appreciated gestures of support they received from their family caregiver. This support was important to patients, not solely for company, but also due to the advocacy and organisational support family caregivers provided to the patient. Many family caregivers prepared for these meetings by noting queries for healthcare professionals as they arose and kept detailed notes of meetings to disseminate information to other family members. This form of support extended from family caregiver presence in meetings to undertaking all information sharing responsibilities for the patient post-appointment:

She [family caregiver] even attends now the meetings I have with the doctors.
(Tom, P14)

I sit in on all of the home visits that take place where doctors and nurses and other medical support people, and I take notes on all of the visits as they happen. I can type as fast as I can write, so I type up I type up all the notes on my laptop as people are talking to her. (Craig, FCG21)

4.2.2.3 Needing to provide constant surveillance to the patient

Some patients, due to end-of-life delirium, medication side effects, or other co-morbidities could not be safely left alone:

The problem is she smokes and does oxygen. She'd pick up the cigarettes... we keep them away from her because she would just light up and so there has to be somebody with her all the time... I can't move outside the house or anything. I'm in the room all the time with her. (Seamus, FCG17)

Although some family caregiver reported anxiety when separated from the patient, some patients were also highly demanding of the family caregiver's attention and physical presence. Such patient expectations of their family caregivers caused anxiety for many family caregivers, particularly for those who felt they were neglecting their own family including their dependants to be with the patient:

She doesn't realise like I'm trying to look after my own house, my granddaughter and her. So she doesn't realise how much I have got to do, but she does say I do too much like. I'm trying my best. (Rebecca, FCG18)

4.2.2.4 Performing household tasks

As previously explained, due to deterioration in patients' physical condition, the reciprocation of physical support between patients and family caregivers was often difficult if not impossible. This resulted in the majority of household tasks been left to the family caregiver and other family members. Indeed, in many cases, family caregivers now undertook everyday tasks at home that the person whom they now cared for would ordinarily have undertaken:

Then there is also kind of small things like answering the telephone... answering telephone calls on the landline or answering the front door... It's just operationally physically difficult for her to do in time. (Craig, FCG21)

Of note, the above tasks proved difficult for some family caregivers who in some cases were elderly or had mobility issues themselves:

I'm on a walking stick, it takes me each trip... Like, if he [patient] wants to have a bit of toast, that's four trips for me in the living room because I can only carry one thing. As in a mug of tea for him, a bit of toast for him, the bit of toast for me, and finally my cup of tea. (Teresa, FCG3)

4.2.2.5 Providing personal care

Personal care was both difficult for family caregivers to give and difficult for patients to accept. Patients' maintenance of their own personal hygiene was considered by family caregivers to be the key to dignity retention for patients and was only undertaken by family caregivers at advanced stages of patient illness and/or when patients had encountered a significant reduction in their functional mobility. Mindful of the potential loss of dignity for patients, this form of family caregiver support was generally executed as quickly as possible and without outpourings of thanks from the

patients that other more easily accepted forms of physical support induced. Family caregivers understood the distress experienced by patients and wanted to protect the patient's dignity:

Well, he relies on me most by changing the nappy and like the private bits, and different parts... you know with the carers, the bits that embarrass him. It's good to leave him with a bit of dignity... He is my husband. I think it's all about his dignity. (Mary, FCG13)

However, whilst family caregivers highlighted their attempts to support the patient, patients also reported on the negative aspects of such family caregiver effort particularly when they felt they had been infantilised by family caregiver support:

The days I don't like... I was back in the hospital, four or five weeks ago, and I don't really remember I was going down for my treatment, and I don't really remember leaving the house, and Teresa pulled me along like a child and got me there. (Stephen, P15)

Hence, some family caregivers also sought to restrain themselves from providing absolute full care to the patient because they were aware of the patient's need to maintain a sense of dignity in their own care:

I was helping him kind of with the washing end of things, but my Dad is so old school and so proud, I wouldn't be able to wash his private parts. He done that himself. I just done anything else. And just stepped out of the room while he done his own private parts. Because he is old school and women don't do that, kind of crap. And we have to take into consideration, he is 90. So, you leave him with a bit of dignity and a bit of pride. (Frances, FCG9)

4.2.2.6 Providing administrative and organisational support

Family caregivers played a significant role in ensuring patients were benefiting from all healthcare processes to their fullest, including transporting them to their appointments, training themselves on the administration of physical care, and ensuring medication adherence for their ill family member:

The hospice are prescribing drugs for different aspects of treatment, and that they are important to be taken, and Teresa and I will sit down and discuss it.

(Mick, P3)

Patients felt that they would be unable to fulfil any of these tasks alone, primarily due to fatigue, physical incapability, and cognitive ‘fog’ related both to their illness and medication. Overall, family caregivers’ amalgamation of these duties required advanced organisational skills and a considerable proportion of the family caregiver’s time.

4.2.2.7 Performing activities outside the home

In addition to obligatory healthcare-related meetings, family caregivers reported bringing the patient outside the home for leisure and respite activities. Whilst these activities could be mutually enjoyable for the family caregiver and other family members, family caregiver intention for doing so was to reduce patient’s confinement in the home:

We want to be able to bring my mam out and like to like hotels because she can’t fly anymore like. We had like a year like that she was... she was having like so much fun... like bring her out more places and stuff like that. And enjoy... rather than her being staying in bed all the time. (Kelly, FCG6)

Such outings were selected dependent on the degree to which the patient was mobile and feeling well. Activities were also selected based on the prevalence of falls and accidents in the period preceding the outing. Hotel stays and holiday bookings were frequently cancelled and rescheduled when patients lost energy or appetite. Family caregivers understood the importance of creating normality for the patient and even participated in the ‘acting out’ of normality, such as bringing the person they cared for to settings beyond the home in the context of their expressed wished and perceived needs:

I was able to get up and get dressed and have a shower without any problem. So, I want to be able to do that and then to be able to go out and have dinner,

well I can't eat but to be able to even go out, pretend I'm going for a meal. But just to be able to go out and even walk on the beach, to be able to do things like that. To be able to do and feel good for a while. (Louise, P6)

4.2.2.8 Making allowances for patient irritability

Regardless of the quality of the relationship between patients and family caregivers, family caregivers reported making allowances for the patient's irritability, mood swings, and sometimes, their ill family member's aggression. In addition to providing physical, emotional, and organisational support, family caregivers had to become resilient to what they perceived as hurtful behaviours from the individual they were devoting the majority of their time to care for:

We have our little arguments. Sometimes he'll get a bit narky with me and I'd give out to him then. He would have bad days and that but some days, he gets agitated and a bit narky and a lot of temper comes out when he's in pain.

(Mary, FCG13)

Family caregivers had to judge whether the patient's decisions were being made in the context of patient irritability or irrationality, or whether the patient was clear minded at the time of decision-making. This was a particularly difficult task for family caregivers who whilst observing the effects of medical treatments on the person they cared for, still had to attempt to sway the patient to endure certain treatments particularly towards the end of course of treatment. Whilst family caregivers attempted to encourage the patient to be self-orientated in their decision-making, family caregivers also attempted to bring some rationality to the often-irrational decisions that they felt patients were attempting to make in a state of fatigue, pain, or confusion:

My Dad and I kind of stand back from her initial emotional, knee jerk reaction to it and we try and make a considered evaluation of what's being offered. And then we will work on her, or we'll cajole her into taking the treatment, or if we feel that it is just such a big personal decision that only she can make it, then we'll tell her... we'll tell her our opinion, but that it's up to her. (Craig, FCG21)

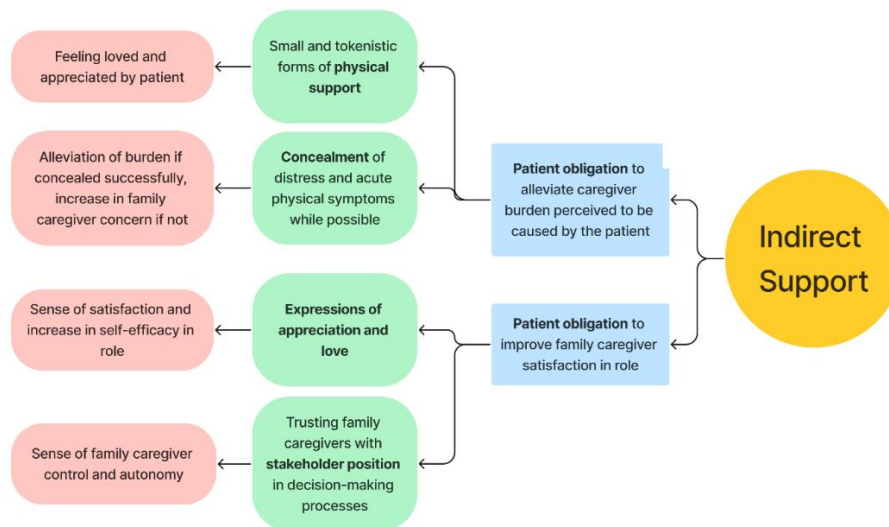
Some family caregivers often alluded to their perception of caregiving as a thankless job at times, with many family caregivers experiencing acute distress as a result. Family caregivers perceived the patient's behaviours to be demanding when they felt that the patient was unable to recognise or apologise for their behaviour:

The pressure that she might put me under some days, looking for things, she would never have been like that before. So, the cancer is probably gone up to her brain, that's why she could be quite childlike, and you know she might make a mistake, she's not thinking in the way she used to think I suppose with certain things. (Sarah, FCG4)

4.3 How support was reciprocated by patients in different ways to the support they received

Patients generally found their inability to perform their pre-morbid supportive roles particularly difficult to cope with. This was particularly prevalent in cases where supportive acts and behaviours were linked to how the patient perceived their own caring role such as being the member of the household that was the primary driver, who performed maintenance work in the home or who may have been the primary source of income to the household. As stated, many of patients' traditional forms of support provision to their family caregivers they could no longer provide and subsequently needed support from their family caregiver to compensate for deterioration in their own physical abilities. However, patients still strove to provide support where possible to their family caregivers within the limitations of their illness through the actions and behaviours outlined next in sections 4.3.1 to 4.3.6. Examples of forms of support indirectly reciprocated by patients are illustrated in figure 5 (pg. 104).

Figure 5. *Examples of patient indirect support to family caregiver*



4.3.1 Compensating through emotional care

Family caregivers' diminished abilities to reciprocate in forms of physical care meant that patients commonly reciprocated by providing emotional support to their family caregiver. Of note, patients attempted to over-compensate in their provision of emotional support (for example, expressing concern for their family caregiver and encouraging self-care behaviours in family caregivers) because of their lack of ability to provide other forms of support to their family caregiver:

She starts asking me about you and 'How's the kids?' and 'Are you okay?' and 'How are you finding the job?' (Niamh, FCG20)

Patients repaid family caregivers with often uncharacteristic expressions of love and praise. This form of care had high value for family caregivers regardless of their pre-morbid relationship with the patient. Moreover, this form of support appeared to be particularly effective for patients and family caregivers where they reported not having had an emotional relationship before the patient's diagnosis. In this context, some patients' perception of their limited time remaining with their family caregiver removed some of the barriers previously inhibiting them from expressing their emotions in this way:

Knowing your body is breaking down, that means I just keep telling them I want to tell them I love them all the time like. (Louise, P6)

4.3.2 Attempting achievable tasks

Family caregivers broadly discouraged patients from partaking in physical tasks. However, certain exceptions applied to this discouragement and included light tasks that the family caregiver deemed to be safe for their ill family member. Tasks that were most beneficial were those that made both the patient and family caregiver feel they were supporting each other:

I suppose she needs to sit back and relax instead of being on things all the time, you know. I try and help out if I can. (Mick, P3)

Of note, a lack of necessity for patients to perform these tasks differentiated them from the essential tasks performed by family caregivers such as providing food and medical care to patients. Despite the reported lack of tangible physical value of these sentimental tasks to the family caregiver, this form of support was nonetheless stated as being important by patient participants:

We alternate we'll say a breakfast. And when it's my turn I'm glad to go down and do it for her because she does so much for me. She will do her little bits on that particular... on the alternate day. (Charlie, P10)

Family caregivers communicated that they could more easily perform such physical tasks themselves and most likely would not allow patients to perform them unless they had value to the patient. While these physical acts were important to the patient to retain dignity and were perceived by patients to relieve the family caregivers' responsibilities, they often caused more distress to family caregivers due to risk of injury to the patient:

I came in to put the kettle on and when I go back in, she's standing up, saying she's cleaning the fire and the mantelpiece, and I say 'Mam what are you doing? I'll do that', and I'm giving out to her, then I end upset because I'm giving out to her... that's just how she is, you know she sees a bit of dirt, she's

used to, that's what she always would have done was get up and clean it, you know where I'm saying she could have fell and whacked her head. (Sarah, FCG4)

Importantly, such actions although physical in nature was perceived by both patients and family caregivers as a gesture of emotional support from the patient to the family caregiver.

4.3.3 Seeking to maintain pre-morbid forms of family caregiving

In some cases, patients felt that that they themselves did not want to be recipients of support from their family caregiver. Nonetheless, they tolerated receiving support from their family caregiver out of obligation to their family caregiver. These patients sought as little support as possible even where fundamentally needed and they expressed that they only allowed support to be given to them in order to appease family caregivers. This pattern emerged in cases where patients were being cared for by female caregivers, typically the daughter or wife of the patient:

I know she's wound up about the whole thing [providing care] and unless she was there, she wouldn't be happy. So, I let her go along. And she's happy to go with that and she's looking around to do different things all the time. If it keeps her happy, it makes me happy. At the moment, it's more for her than me. (Tom, P14)

In cases where adult children were living at home with their parent who was the patient and still to some degree dependent on their parents, the retention of emotional support from the patient was important to both patients and family caregivers. In these cases, the family caregiver was appreciative of the patient's willingness to continue to emotionally support them as their adult child:

Even though she's sick, dying... she's still trying to help you work through your stupid, little problems that you have because she knows that they're big problems to you, she's making sure... she still makes sure that you're okay, that you can pay your mortgage, and is your car okay and are the children and everything fine. She still worries about everything. Now obviously that's a mother's job, they're always going to do that for their kids. (Niamh, FCG20)

Patients who were parents held this support form in high regard, seeing it as their central role as a parent, and were generally unwilling to renounce it regardless of whether their (adult child) family caregiver resisted or not:

She keeps everything in you know and sometimes it's very hard to get stuff out of her you know? Sometimes I chisel away at her and she breaks down and tells me. (Neil, P7)

4.3.4 Attempting to 'look well'

Patients felt that they were supporting family caregivers by attempting to conceal their illness by efforts to look well. Patients perceived that this effort was warranted as it appeared to evoke a reaction within their family unit, seemingly putting family caregivers at ease on seeing the healthy appearance of the patient. In these situations, patients hoped that their family caregiver would view the patient's appearance as a sign of the patients feeling well. Whilst this might not necessarily have been the correct assumption to be made by the family caregiver, it was the motive behind the patient's efforts:

If they see me look rough and hot and bothered then they know things... there's something wrong but I literally every day, I'm just very physically... I make sure I'm in shape. (Frank, P5)

4.3.5 Inviting family caregiver input in decision-making for care

A significant change in roles took place in the process of decision-making about patient care. In cases where patients who previously would have made decisions alone, were now more inclined allowed family caregivers to become stakeholders in decision-making. This behaviour was deemed in itself a form of support by family caregivers who were grateful to be listened to and heeded in contexts where they would have otherwise been previously submissive and accepting of the patient's wishes. This behaviour was most frequently observed between the patient who was a parent and their family caregiver their adult-child. Patients who allowed their family caregivers to

take up a stakeholder role in decision-making enabled their family caregivers to feel empowered and feel in control in their caregiving role:

He gets me and my sister's opinions on stuff as well, like we decide as a family... It's not really like a one-sided kind of thing like 'this is what I want to do and you're not going to tell me different'. Like we're always included. (Isabella, FCG7)

Family caregivers perceived that the efforts displayed in their caregiving for the patient led to having earned their position as stakeholder and which in turn enabled them to further support the patient both in an advocacy and information gathering role for the patient. Indeed, patients considered this a highly valuable form of support because of a deterioration in their ability to concentrate or retain information imparted to them about their treatment and care:

We have been, like alarmed on one or two occasions with the extent of the [medication] dosage. One or two of the more senior drugs for the want of a better word. She'll [family caregiver] spot it as well as I will you know, yeah. And, you know, her input to me is, is really very, very welcome. You know ... she doesn't really miss anything. She's a good listener. (Mick, P3)

4.3.6 Bolstering family caregivers' self-worth through encouragement

As already outlined, patients found new ways of supporting their family caregiver in their new roles and in the context of their changing circumstances. Patients acknowledged that while their ability to support their family caregivers had changed in certain ways, the needs of their family caregiver had also changed. Although patients found that the ways they could support their family caregivers had been restricted to emotional support, they also found that their family caregivers need for emotional support from them had increased. This made providing emotional support to their family caregivers feel valuable particularly in cases where the family caregiver's need for emotional support from the patient had been less in the past. Patients found purpose in supporting their family caregivers in this way, which in turn had benefits for both patients in their self-worth and for family caregivers in terms of feeling

appreciated and cared for by the patient. These scenarios were evident between patients who were parents and where their adult child was their family caregiver. Adult-children family caregivers highly valued the appreciation and validation given to them by their parent because it also aided them in their own self-care:

She [patient] does tell me what she wants, and you know how she's feeling, she does say to me you know... 'I don't know what I'd do without you', stuff like that [...] she does appreciate that we try our best for her. (Rebecca, FCG18)

Patients encouraged their family caregiver to be mindful of their own self-care through advising them to take time apart from them and to enjoy leisure activities, socialise with others, and attend to their responsibilities that still existed for them outside of their caregiving duties:

He would suggest 'Why don't you go down to your sister and go for a cup of coffee with them?'... He would say 'Oh of course, of course, go! You need a break as well'... He is considerate that way. (Anna, FCG5)

Some family caregivers acknowledged the importance of their own self-care for their stamina while caregiving even though they perceived that there seemed to be no appropriate time to take respite without potential risk to the patient. Here, family caregivers' attitude towards their own self-care was influenced by the degree to which the patient supported them by encouraging and not inhibiting their self-care behaviours. Some patients with varying degrees of cognitive difficulty were viewed less likely by family caregivers to emotionally support them because of fluctuations in their cognitive status:

I mean, like some days you go down and talk to her like you used to talk to her, you tell your problems and then halfway through the conversation you realise... there's no point in saying that, and she's forgotten what I've just said or she'd read into it wrong because her mind's not working right and it's those kind of things. (Niamh, FCG20)

However, for the most part, patients, encouraged family caregivers to take intermittent breaks in the caregiving role for the benefit of their family caregiver

wellbeing. In such situations, some patients also supported family caregivers by rallying other support from formal services to relieve the primary family caregiver in their caregiving role:

My sense of trying to support Laura [family caregiver]... is to check in with Laura that she has somebody that she can speak with. (Ian, P2)

I want Pauline [family caregiver] to get some of her own life together and not mine all the time. So, she's happy doing that and I know that if I need to give palliative care a bell or the hospital... And as I say, once I know that they [palliative care services] are there, I'm happy. And it means then let Pauline go to do to her own bits of stuff as well. (Tom, P14)

4.4 Chapter conclusion

This chapter has shown that support between patients and family caregivers was exchanged directly and indirectly. Direct support involved behaviours and actions which mirrored the other's actions and behaviours. Indirect support involved support given by one and repaid by the other in a different form. Patient and family caregiver provision of support to one another was deemed by the patient and family caregiver to have positive effects for both. Patient and family caregiver shared coping and creation of a shared reality allowed intuitive care to grow between them and made supportive behaviours and actions for the most part, acceptable to the patient and family caregiver. However, patient and family caregiver ability to intuit the needs of their respective other could also reduce discussion around wants, needs and expectations.

Support from family caregivers was both physical and emotional. Despite patients' best efforts, many patients felt they could not reciprocate support to the same extent that they received it and particularly if reciprocation necessitated the provision of physical support or indeed high level of emotional support. However, regardless of how much patients willingly accepted or struggled to accept the support they received from family caregivers, they attempted to repay their family caregivers' efforts through encouragement, expressions of love and appreciation, and by showing

concern for their family caregiver's strain. Family caregivers often stated that the best form of support they received from the patient was the patient's encouragement of and gratitude to them in their role as a family caregiver. Family caregivers tended to strongly prioritise patients' needs over their own and could be satisfied in their caregiving role when they perceived their support provided to the patient to be of benefit to the patient. Overall, patient and family caregiver provision of support to one another was motivated by their mutual need to support one another. Patients and family caregivers provided support to each other out of mutual responsibility to one another.

This chapter has detailed evidence that patients and family caregivers in palliative care can be mutually supportive. To help enable supportive relationships between patients and family caregivers in palliative care, it is important to consider what are the key factors that facilitate and/or restrict mutual support between patients and family caregivers. The next chapter (chapter five) reports key factors which enabled and restricted mutually supportive relationships between patients and family caregivers.

Chapter 5: Facilitators of and Barriers to Mutual Support between Patients and Family Caregivers

Chapter 5: Facilitators of and barriers to mutual support between patients and family caregivers

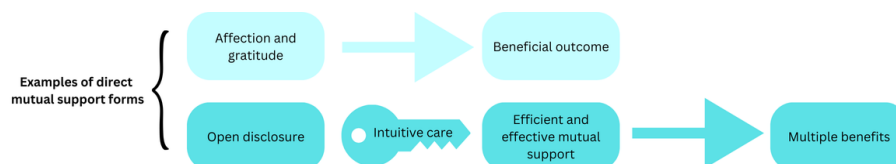
Chapter four reported on key processes, behaviours, actions, and interactions that comprised mutual support between patients and family caregivers. This chapter outlines key barriers to and facilitators of mutual support between patients and family caregivers and explains how factors both within and external to the patient and family caregiver dynamic impacted on the capacity of patients and family caregivers to be mutually supportive.

5.1 Facilitators of mutual support between patients and family caregivers

5.1.1 Open disclosure between patients and family caregivers

As discussed in chapter 4, open disclosure was a form of direct mutual support. However, some support forms also acted as facilitators to further development of mutual support. The difference between support forms that have direct, instantaneous benefits and support forms that ‘unlock’ further opportunities for mutual support are illustrated in figure 6 below.

Figure 6. *Direct and facilitative support forms*



Open disclosure, while a key process of mutual support, was also effective in patients and family caregivers discovering how best to support one another and was therefore a support form and a facilitator of mutual support. Disclosure concealment of emotions, thoughts, or symptoms allowed for more accurate understanding of each other’s perception of their circumstances and needs. Without this information, the support given by both patients and family caregivers to each other could be impeded

due to the misunderstanding of perceived needs versus actual needs of the other person. Open disclosure enabled patients and family caregivers to understand each other's perspective. This allowed both patients and family caregivers to form a sense of predictability of each other's behaviours due to the honesty and openness of their communications, rather than be blindsided by patient irritability or family caregiver burnout that might otherwise occur in situation where mutual distress was concealed. Open disclosure also allowed for the family caregiver to become highly informed about the patient's perception of their circumstances, allowing them to advise in decision-making processes in line with patient wishes. This in turn enabled family caregivers to perceive that they were gaining some control in their caregiving role:

We talk about everything. Like we've never been like, anything hidden, he [patient] always talks about what he wants to do and his decisions and stuff like that. (Isabella, FCG7)

Mutual support between patients and family caregivers was strengthened when efforts were made by either patient or family caregiver to be more expressive than they had been, before the patient's diagnosis, in terms of open disclosure:

I didn't tell [family caregiver] my problems, but now I am because I'm just being sick... I think this is the first time I've told them how I'm feeling which is very important I suppose. (Louise, P6)

5.1.2 Being intuitive about each other's needs

Similarly to open disclosure (section 5.1.1), the intuition that patients and family caregivers developed through a clearer understanding of each other's motivations and needs was both a result of direct mutual support and a facilitator to efficient and effective mutual support. Open disclosure between patients and family caregivers at the beginning of the palliative care experience resulted in mutual understanding of the needs of one another, which in turn could result in less conflict and a more positive patient and caregiver relationship. As represented in figure 6 (pg. 113), intuitive care is the facilitative result of open disclosure. Once patients' understanding of the most effective way of showing thanks and appreciation for the family caregiver was

established, family caregivers felt bolstered in their caregiving role, more appreciated by the person they cared for and fulfilled in their caregiving role. Patients and family caregivers who were open about their needs early in the palliative care journey were able to identify each other's concealed emotions and wishes which in turn promoted further open disclosure and minimised future concealment:

I hide nothing from them [family caregiver]. Absolutely not. That's why I said before, we're so close. You know, we're so close and a unit ... I can't hide anything from you know. They know my moods, and they can tell if there's something wrong with me... they could tell right away. (Neil, P7)

We've had that close relationship, like through our entire lives so it wasn't difficult on the way in that sense... I think we've gotten even closer since the diagnosis. (Isabella, FCG7)

Importantly, open disclosure enabled family caregivers to providing support and care without having to be prompted by patients' requests and assisted family caregivers in discerning what patients would request in decision-making should the patient be unable to engage in the decision-making process:

She knows exactly what to do... she's also fully aware of what I need. (Mick, P3)

5.1.3 Being supportive of each other prior to patient illness

Patients and family caregivers in relationships where they felt they were already accustomed to taking care of each other, such as within spousal relationships, indicated that they continued to be mutually supportive of each other even when confronted with the challenges of living with terminal illness:

We make all decisions together and that's the way we have done it. Like, even from when my mam was sick before she died, that's just the way we've done it, we made the decisions... we would have sat down as a family and we made a decision on what had to be done or whatever. And it's just the same now. (Jen, FCG16)

Being supportive of each other prior to the patient's illness was also an important context to when the caregiver and care recipient swapped roles such as when a parent became the care recipient, and the adult-child assumed the caregiving role:

I think because... because he's my Dad, and I watched him, all my life. I was always close to him, and I've watched him go from a big man, down to what he is now. And that's not nice. That's not nice, because he's always been my protector and even when I was married with children and what have you, I was always a daddy's girl. (Frances, FCG9)

Sections 5.1.3.1 to 5.1.3.4 further describe the impact of past supportive behaviours on relationships between patients and family caregivers.

5.1.3.1 Pre-existing reciprocity in the spousal/partner relationship

Spouses and partners had previous experience of navigating difficult and complex decisions prior to their respective other's illness including decisions regarding their shared caregiving of dependents, financial decisions regarding shared assets, and decisions made in previously challenging situations such as bereavement and prior illness. In these situations, both patients and family caregivers referred to the historical context of being supportive to each other to enable them to receive support from and provide support to each other. Patients and family caregivers who were spouses or partners appeared to find it easier, when compared to patients who were parents and their adult child their family caregiver, to accept care from their respective other:

There are certain things that I can do to help the situation with Maggie. And we sort of marry one another in that respect. I give Maggie help in whatever way and again, she gives it to me a hundred-fold... the benefit of having somebody is enormous and we were always at that persuasion anyway. But it sort of works a little bit more in our favour now because we're grateful for what we have around us. (Charlie, P10)

Several features of the spousal relationship appeared to alleviate the difficulty of adjustment to living with life-limiting illness. Participants in spousal relationships shared life-long experience prior to the patient illness that required shared navigation and decision-making. Subsequently, changes were not solely happening in the life of the patient, but also in the shared life that both had already experienced together:

Throughout the years that we've been together, we've always been able to talk... we've a good, you know, a very, very high level of understanding between one another, and we're able to sort a lot of things out just by kind of sitting down like and saying like 'Look, maybe... maybe this is what we should do' or, you know, making suggestions or making plans and things like that. (Eamonn, FCG1)

Of key importance was the fact that spouses were generally at the same life stage as each other, allowing them to develop shared perspectives and concerns and to find common ground. Such context also meant that as there could be open disclosure about mutual concerns, particularly mutual concern for their dependants:

Matthew was diagnosed on [date], our daughter was getting married [ten days later]. So, we actually had to absorb that information, and then try and park it until the wedding, because we didn't want the kids knowing before the wedding. When we had to tell our daughter after coming back, [we said, we] couldn't tell you but you have our word that everything, everything is open and on the table now. (Carolyn, FCG12)

Spouses and/or partners also had a shared history where one partner may have required the support of the other disproportionately at one point in time during their relationship. Within this relationship, there appeared to be a predetermined understanding that the person who now required additional support would receive it from their respective other. This undertaking of the caregiving role by default appeared to make the transition to the caregiving manageable for spouses or partners. The significant disruption to their normal shared lives appeared to make it easier to take up their new roles in the knowledge that attempting normality and resisting change would be futile. The above was a feature among participants who were

spouses and who were already sharing their life with each other and who had prior to the patient illness and who anticipated growing old together. These participants felt that the patient's diagnosis was a shared issue and so necessitated the getting emotional support from each other:

He had so many friends and all of that, that sometimes you might have thought before that that even though you were important that you weren't actually that important... You wouldn't be relying on him ... [but] he has he started to say a lot more about how important his family are and that at the end of the day, 'Nothing else matters' he would say to you, 'So long as you are okay.' ... That's actually quite good for me to feel like that. (Tina, FCG8)

As a result of living with the patient, spousal family caregivers suggested they were able to gradually increase the degree to which they gave support, and which allowed them to transition effectively to a caregiver role. Living together also facilitated understanding of each other's needs which in turn enabled open disclosure and made distress difficult to conceal from one another:

In terms of [family caregiver's] and my mental health, we were doing everything we could, or we thought and tried to do everything we could [to emotionally support one another] ... We're good together, very good together, and [he's] very good with me but we have our crying evenings. (Michelle, P11)

For the majority of participants in spousal relationships, they felt their relationships remained relatively stable and equal despite the changes to the household and because their navigation of past challenges. This allowed spouses to share the power over how they dealt with their circumstances particularly when navigating challenges:

We don't tend to have emotional breakdowns... We don't express ourselves like that, we talk through everything. And so, you know, there has been a couple of tears shed, I won't say there hasn't, but on the whole, that's not how we deal with things, we kind of get up and dust ourselves off and just get on with it, that's the way we are. (Irene, P1)

5.1.3.2 Having a strong (pre-morbid) relationship with one another

A key facilitator for building or maintaining mutual support between patients and family caregivers was the pre-existence of a strong pre-morbid relationship. The pre-existence of mutual understanding, the navigation of shared historical challenges, and previous reliance on one another facilitated their collective ability to adjust to new and difficult circumstances. Relationships that were positive and low in conflict before the patient's diagnosis generally those reported to by participants to have transitioned into relationships where patients were open in their disclosure to family caregivers and were also grateful and expressive of love:

He gets me and my sister's opinions on stuff as well, like we decide as a family... So like we've had that close relationship, like through our entire lives so it wasn't difficult on the way in that sense. (Isabella, FCG7)

Importantly, strong pre-morbid relationships between the patient and family caregiver enabled family caregivers generally to self-appoint into a family caregiver role, leading to feelings of empowerment in their caregiving abilities and feeling satisfied that they were make a significant contribution to their respective other during the remaining time they had together. Indeed, some family caregivers who had strong pre-morbid relationships with the person to whom they were a caregiver took pride in the fact that they were the primary caregiver on whom their patient relied most heavily:

Knowing that I'm doing my best for him... knowing that I didn't... let somebody else take care of him. That's what kind of gets me through the day. And knowing that if he calls out, I'm here and it's me that is looking... That's kind of what gets me through. I always said that when he dies, my conscience will always be clear because I've done the best for him [while caregiving]. That's what gets me through it. (Frances, FCG9)

5.1.3.3 Expressions of love

Patients who reported that, prior to their illness, they had already tended to be expressive in their affection to their family caregiver, reported that this emotional support given from the patient to their family caregiver was maintained post-diagnosis. The majority of family caregivers in the study expressed feelings of comfort on receipt of these expressions of love and they appreciated the gratitude displayed by their ill family member to them:

I suppose, just holding my hand... just saying I love you and she does always say 'Thanks for everything you do for me', and 'You're an angel and there's no one like you.' ... it makes me feel that she's happy with me and I'm doing good for her. (Sarah, FCG4)

5.1.3.4 Adult-child family caregiver repaying support already received

While spousal relationships had many features which facilitated mutual support, parent and adult-child relationships also had characteristics which enabled mutual support. Adult children who were caregiving for their parents sometimes felt as if they were repaying a caregiving debt to their parents who had provided care while raising them when has been dependants of their parent. Of note, taking this attitude towards caregiving appeared to alleviate feelings of being trapped or forced into a caregiving role:

I would love to... to help my mam, like you know because she's done so much for us as a single parent, like she was always there like, so I think that would be nice to return the favour... like if it ever got that bad and obviously it's her decision, but me and my sister would love to help out and obviously would have to leave our job and be a carer but that wouldn't be an issue really. (Kelly, FCG6)

Family caregivers who were caregivers to their parent and who felt indebted to their parent were readably able to overlook personality changes in their ill family member. This contrasted with some spousal family caregivers who felt uncomfortable with personality changes in their partner because of the disruption such change had on their previously equal roles for navigating their daily lives. Adult-children caregivers

understood their parent personality change to be an expected part of their continued relationship:

Some days I think she thinks she doesn't need us at all... another day she'd be saying what would I do without you because she'd be getting up out of bed and she can barely walk and you've to carry her to the toilet and helping her with everything, like she thinks she can go and do everything but then she stops and you do it for her, and she relies on us for absolutely everything, and that's absolutely fine. It's our turn now, that's how we look at it. (Niamh, FCG20)

5.1.4 Family caregiver self-appointment to a caregiving role

A significant facilitator of mutual support between patients and family caregivers was family caregivers' ability to have some control over their own role as a family caregiver including the choices they made in the context of being a family caregiver. Indeed, family caregivers' satisfaction in the caregiver role was explained in part by the fact that appointed themselves to a family caregiving role. Moreover, family caregiver participants who opted to assume caregiving duties over other family members generally felt more confident in the role:

I would have always ... been the one who does the most caregiving, and my brothers, while they live beside my father, they don't [provide care] ... [to me] it comes naturally ... I kind of nearly thrive on that being able to help. (Pauline, FCG14)

Family caregivers' sense of comfort and satisfaction in their role was related to how much choice they had over being nominated by themselves or others into the family caregiver role. Those who chose to put themselves forward felt that they themselves gained self-satisfaction and calm due to their control over their altruistic efforts. This kind of supportive behaviour also appeared to ease feelings of resentment against other family members who were not offering the same degree of support:

It's easier for me because I actually live with him, but I think if I didn't live with him... it would take more of a toll on me personally, but because I'm actually here with him and I know where everything is, I can put my hand on everything,

whereas if I was only coming up to see him, and if he lived with one of me brothers or something, I'd be like, 'Where's this? Where's that? And why is this not happening with him? Why is that not happening with him?' Whereas I'm here... it's easier for me because I actually live with him. (Frances, FCG9)

Indeed, family caregivers who deemed themselves the best candidate for the role of primary caregiver volunteered or undertook more care because they appointed themselves into a caregiving role:

It's just my own personal feeling that you know, the physical support is just a natural... a natural action, I suppose by my own nature... I'd be kind of like a bit of a restless person anyway, so I'd always be pottering about doing something as it is, so I think that's just second nature. (Eamon, FCG1)

However, other family caregivers volunteered to undertake the role due to their lack of faith in others to carry out caregiving duties to their standard. These family caregivers indicated that they felt more in control of their own circumstances if they undertook majority of the patient's care at home:

I know sounds sad... It does sound selfish. And I know it sounds selfish. But if I'm in control, I'm in control of me. So, if I'm in control of me, I can do what's necessary. So, if I'm in control of the situation, I know what I'm doing. (Frances, FCG9)

The belief of the primary family caregiver that they were the most proficient of all other family at delivering care allowed them to believe that they undertook all care by choice. Of note, this belief also helped relieve some family caregivers from feeling that they had been forced into the role of caregiving due the inability of others to care:

It's mostly me and [my sister] take turns staying here every night, every other night, so then I'm here when she works, so I'm here most of the day ... then in my own house I get in and get anxious [when sister is caring for patient] ... I suppose it just comes to me naturally, I don't know. Like it's just worth having [patient] at home and being able to care for them. (Maria, FCG15)

5.1.5 Family caregiver competence in a caregiving role

Family caregivers' perceived choice in taking up their caregiving role was in some cases underpinned by their self-assessment as a caregiver. Family caregivers who deemed themselves as family-orientated individuals and possessing caring traits generally felt more comfortable stepping into the family caregiving role than those who did not consider themselves as 'natural caregivers'. Family caregivers who did not feel they possessed these traits felt that they did not settle into the role as comfortably and could not always intuit what actions to take for the patient. Of note, family caregivers with pre-existing caregiving skills saw their role as an extension of their own personality, allowing these caregivers to draw from these pre-developed traits and provide care intuitively to the person they cared for:

When there's something wrong, we talk about openly and you know, we use a bit of humour to through things but we're working both very well. With my history and social care as well, I would be used to dealing with trauma and things like that. (Pauline, FCG14)

Patients felt they tended to settle into the receipt of support more naturally if their family caregivers already had caregiving skills. Moreover, when caregivers did not have to change their behaviours to become a family caregiver, patients felt less burdensome and unsettled by the caregiving role assumed by their family member. When patients deemed family caregivers to be well equipped to be a family caregiver in the context of their already established familial roles, patients deemed that their family caregiver's transition to their caregiving role was more of continuation of their existing roles and not necessarily a discontinuation from their life together before the patient's illness:

That's the way she is, I think that's the way that I think is say... more of a woman than a man. A man wouldn't give a fiddlers! But she wants to... everything. She's very... she's overprotective. I kept telling her, there's is no need for it, I know what to do. She was really protecting me, which is natural. (Michael, P2)

The degree to which family caregivers were engaging with palliative care services available to the patient and family caregiver also seemed to bolster their (i.e., family caregiver) confidence. The more family caregivers sought out advice and training, the more they felt able to enjoy aspects of their caregiving role and without fear of not been able to successfully deliver care:

I just wanted to just kind of like, see anything I can do to help my Mam. So I wanted to go in and just talk to somebody. So, in the last two weeks, so two weeks ago I was speaking with one of the social workers there. I went into hospice, and I found that really helpful. So, I have to see her in another two- or three-weeks' time. (Kelly, FCG6)

In some cases, the experience of having to navigate challenging circumstances could make family caregivers feel effective in a caregiving role. In addition, this could change family caregivers' view of their own abilities in their caregiving role, particularly if they followed advice from formal services:

I have to be honest, since they [specialist palliative care team] came in now in January, into here into my situation, I've kind of learned more in the way of caring for my Dad, as I said, listening to him and watching out for the signs, telling me what to watch out for, telling me how to deal with the medication, and telling me to kind of use my own judgment. (Frances, FCG9)

Importantly, patients also benefited from their family caregivers' self-confidence in their role as family caregiver. When family caregivers appeared to be calm and confident in their demeanour, patients were put at ease and expressed trust in their family caregiver. Indeed, family caregivers' ability to remain calm and confident in the face of adversity was valued strongly by patients:

Her [family caregiver] calm demeanour would be the one to the fore I suppose because as I say, she doesn't panic. She doesn't get into a tizzy over anything. As we say if there's a problem, we see it and sit down, have a look at it. We both will. She's really calm in her nature. It wouldn't cause her, you know, a thought to give me an injection, or anything like that, she's a really practical sort of person. (Mick, P3)

5.1.6 Support from other family members and friends

Mutual support between patients and family caregivers was facilitated by support from other family members. This was particularly effective when the family caregiver was listened to and respected within their role by other family members. It appeared to be more beneficial for both the patient and family caregiver when the family caregiver was perceived by all as the primary caregiver with other members in the family assuming secondary caregiver roles. Support from the wider family was deemed helpful by family caregivers:

I would be obviously the main carer. My two brothers and my sister, they're obviously in the background, they come in and out during the week to him. Like anything at all that I need, they are there in the background with him ... he has a lot of grandchildren as well. (Jen, FCG16)

Sections 5.1.6.1 and 5.1.6.2 explain how support that patients and family caregivers reported available from the wider family helped both patients and family caregivers cope with the demands of the patient's illness.

5.1.6.1 Delegation of duties by family caregiver to other family members

An important feature stemming from wider family support that was the primary caregiver's ability to delegate duties to other family members. Delegation of duties was dependent on other family members' willingness to undertake assume caregiving duties. Other family members' ability to assume duties facilitated mutual support between patients and family caregivers because it helped reduce the family caregiver's amount of time spent on daily caregiving tasks which in turn allowed them to increase their time spent with the patient rather than merely tending only to their care needs. Family caregivers delegated tasks to other family members which included for example, management of patient medication and treatments:

My son now would do a lot of research and on different things and he actually went to one of the appointments with Frank [patient], the oncology, and he asked about what other treatment was available, if needs be and what one can

John access and things like that? So we would... kind of discuss it... He [patient] wouldn't make a decision kind of on his own. (Anna, FCG5)

5.1.6.2 Having a network of supportive friends

For some patients and family caregivers, their wider family unit was characterised as 'tribal' in which both patient and family caregiver needs were tended to by other family members:

I said 'I think I go back to work' and he [patient] said 'You know, I think you should' and the girls, like my daughters were saying 'Look you go back, you only do two or three days a week, if needs be we'll come down when you're in work, if we come down and spend a few hours with Dad, make him a cup of tea or a sandwich or whatever on then days, and if we can't'... my sister said, 'Look, I'll come up and sit with him', so things like that. And so, I was glad to kind of get back to work as well. (Anna, FCG5)

Non-familial based support from patients' and family caregivers' community of friends helped bolstered feelings of confidence in family caregivers and allowed them where possible to maintain varying degrees of normality in their lives:

Friends that I would have thought were just maybe a little bit more than acquaintance, how they rallied around, and the support was just phenomenal. And so, you know, for us that opened our eyes to... how kind people are and how devastated people were at the news, when I got the news that, you know, I had cancer, and I was... I was at a later stage in it. And, and so that, you know, seeing them and seeing how they reacted to it, it made me very humble. It was very, very humbling experience. (Irene, P1)

Overall, support from the wider family and community facilitated mutual support between patients and family caregivers because it alleviated both the burden of care for the family caregiver and patients' concerns about being a burden on the family caregiver. Importantly, patients who felt less of a burden on family caregivers were more likely to accept support from their family caregiver, and family caregivers who

were better supported by the wider family and community felt they had more energy and stamina to give support to the person whom they cared for.

5.1.7 Respite for family caregivers

The prevention of family caregiver burnout was a significant contributor to mutual support between patients and family caregivers. Respite for the family caregiver bolstered family caregiver stamina in a caregiving role. It also gave patients satisfaction to see the family caregiver engage in activities for themselves which in turn alleviated their feelings of burden on the family caregiver and giving them an opportunity to reflect on the family caregiver's sacrifices made in their caregiving role. This period of separation could have positive effects for both patients and family caregivers and helped patients and family caregivers balance their own needs in relation to each other:

I still get up and go to the gym every day... I've always gone to the gym more so for my mental health than my physical health, so I still do that, and I feel like if I've done that, I can look after her for the rest of the day, look after my own family for the rest of the day. I'm not constantly thinking oh God, does she... has she something wrong or does she need something?... I think all of us do little things for ourselves every day I think. I think you have to or you'd find all of us in the loony bin. (Niamh, FCG20)

Respite for family caregivers was either enforced by other members of the family or by friends. Periods of family caregiver respite were particularly important for family caregivers of patients that needed constant surveillance due to risk of falls or injury or because of their cognitive deterioration:

My daughters, two in particular, one... just lives around the corner from me and one lives the house here with us... the two of them are brilliant. If I want to go anywhere they'll come and sit with her [patient]. A game of golf, usually I have a game of golf every week, and one of them will come and sit with her. They have to because of her head the way it is. (Seamus, FCG17)

However, family caregivers who took time for themselves to alleviate caregiver burden did so infrequently and with feelings of guilt and anxiety. Family caregivers who had to afford themselves this time were often already experiencing symptoms of burnout by the time they engaged in the self-care behaviour. Self-preservation behaviours were not only important for family caregivers to alleviate perceived psychological burnout. They also functioned to ensure that family caregivers could to some extent manage their own physical strain. This was particularly prevalent in situations where patients experienced some cognitive deterioration and did not fully understand the repercussions of their actions or demands. In these situations, family caregivers who considered the risk of injury in caregiving were generally better at enforcing boundaries with the patient, ensuring they would be in good health and be able to continue to provide care to the patient:

I'd like her to make decisions as well like if possible... But the likes of going up stairs could be just dangerous, because if she falls back or if I don't catch her, I could hurt my back, so there's some decisions that unfortunately just aren't hers anymore. (Sarah, FCG4)

5.1.8 Feeling supported by healthcare services

The majority of patients and family caregivers in this study indicated that the support they received from healthcare services enabled supportive relationships between them. Healthcare services were deemed by patients and family caregivers to be beneficial because formal services encouraged family caregivers to organise rotas with other family members and participate in counselling, that could serve to alleviate caregiver burden and distress. Family caregivers also felt supported and encouraged by healthcare professionals, particularly in relation to developing their health literacy and upskill in their caregiving roles. However, of key importance, for family caregivers was having access to hospice services to alleviate feelings of isolation and distress during periods of COVID-19:

It's a great support like to have, because with the situation of the hospitals and doctors and COVID, it was so hard to kind of get an appointment with your GP or to get talking to doctors in the hospital. So, it was great to have the backup

of the palliative nurses, and they were on call, whenever, you just had to ring whenever you if you wanted to find out anything or ask any questions, what they were kind of available in that scenario, so a great support. (Anna, FCG5)

Patients frequently commented on their satisfaction with supports offered to them by healthcare professionals. Patients generally felt heard by the healthcare professionals they encountered and felt that any issue or anxiety they had was dealt with swiftly and with consideration. This prompt response to symptom management was appreciated by both patients and family caregivers and alleviated distress for both patients and family caregivers:

Well, I have to say I've found them [healthcare professionals] excellent and very supportive and very anxious to, if I was in pain, which I was in excruciating pain, to try to find a way of alleviating that pain. So, they went through whatever steps they could until... now I can't tell you what drug combination they have found but they have found the combination anyway, but we've had the pain free now for at least a month. (Ian, P2)

I think through a variety of different ways and including [the hospice] as well, like we've had a lot of positive feedback, a lot of helpful input that's given us information, that has given us the ability to deal with a lot of things day to day. (Eamonn, FCG1)

Patients acknowledged their inability to provide support due to fatigue and illness and were relieved that healthcare services could assist them to compensate for their own lack of ability to fully explain their care needs to their family:

I really didn't get to meet the people from the hospice until I came home, and they were pretty quick on the scene I have to say. When they did come, I was very impressed with the fact that my youngest is 21, but she was not sure how to be taking it and they took her side and brought her down to hospice for a little tour and they gave her an idea of what's going on down that way and what they do. That was very helpful for me because my daughter... I've four daughters and a son and they did take it pretty hard. (Frank, P5)

5.1.9 Having trust in healthcare professionals

Patients and family caregivers reported that they were grateful for healthcare professionals in whom they placed a significant amount of trust in. If family caregivers felt that a healthcare professional was honest and trustworthy, they felt that their own skills in supporting the patient were being honed under the guidance of someone that they deemed to be a reliable expert. The ability to contact a healthcare professional who had capacity to relieve distress for both was important for both patients and family caregivers:

I think Paul [palliative care nurse], we've been dealing with the hospice for the past maybe six months. My sister was dealing with him at the beginning, and we just heard Paul this, Paul that, Paul, Paul, Paul, Paul, Paul. I was thinking 'Who is this Paul fella?' So eventually, I was like, I want to meet Paul. Because even now my mam is like, 'Oh, I love Paul' and 'Talk to Paul' and 'You'll have to talk to Paul'. And then I met him one day, and he just has such a lovely way about him. Even the way he speaks, the tone of voice, everything. And he'd tell you the truth as well, in such a lovely way. And so, the minute I kind of met him, I just felt at ease already and I was like, okay, he's going to look after her, he's going to help us look after her and tell us what we've to do, when to do it, and if there's a problem, we can always just ring Paul and it'll be fine. (Sarah, FCG4)

Patient and family caregiver trust in hospice staff also strengthened mutual support between patients and family caregivers because emotional support received from formal services opened up conversation and promoted disclosure between patients and family caregivers:

The care team are actually really good, like when the nurses come up to the house, he [patient] will talk with them and me and they are really, really helpful. Even my Dad says that he wouldn't be super, super deep in like emotions with me, [but] it's just a really caring talk we have with them. (Isabella, FCG7)

5.1.10 Stoicism in the face of uncertainty

Another key factor that facilitated mutual support between patients and family caregivers was both patients' and family caregivers' ability to remain stoical despite the fluctuating and advancing nature of the patient illness. Both patients and family caregivers reporting anxiety about the next stages of the illness and patient care. Nonetheless, both the patient and family caregiver attempted to remain stoical in the face of uncertainty. Shared stoicism between the patient and family caregiver functioned as a shared act of support between patients and family caregivers:

I can't live wondering when it's going to happen ... [but] once you know you're making Pauline [family caregiver] at ease, and everything is going right, and if you didn't have them there you wouldn't know what way it's going or how it's affecting them. (Tom, P14)

Both patients and family caregivers acknowledged that focusing on the present helped them to frame their circumstances to share positive experiences. Being able to compartmentalise future anxieties facilitated patients' and family caregivers' ability to have positive experiences which were intended by them to overshadow their shared fear, anticipatory grief, and anxiety. This was particularly prevalent in interviews where patients and family caregivers were being interviewed together, revealing a shared attitude towards their circumstances, for example in the case of Kelly (FCG6) and her mother Louise (P6):

I think you just kind of push on and to be like positive and try not to talk about cancer as much and just to live normal... and enjoy the moment and live a normal life even though sometimes it's hard. (Kelly, FCG6)

If you're going to sit there and dwell on it and feel miserable about it, you're going to be down. What is that going to do to you? Because at the end of the day you have to give God his good endorsements, you have to get up and say 'Well today is another day, I'm alive, the sun is shining, and something is happening. I'm going to have a great day.' And you say that to yourself. But

what if you got up and you said, 'Oh God I have cancer, I'm going to die' blah blah blah... you're going to feel miserable. (Louise, P6)

Incidences of the patient falling as a result of disorientation or physical weakness because of progressively worsening symptoms of their condition caused distress for both the patient and family caregiver:

There have been situations in the past where things [accidents] have happened during the night, and although like it wasn't with the hospice, it was with the hospital, we would have to wait until the morning to get that sorted, and it was extremely anxious for everybody. (Laura, FCG2)

However, reframing the palliative care experience from one which they initially perceived as a stable yet steadily advancing process to one in which instability and fluctuation predominated, helped patients and family caregivers deal more readily with unanticipated events. These events included unanticipated accidents such as falls and acute and/or sudden pain and the receipt of medical test results showing unexpectedly severe illness progression. Although the fluctuating nature of the patient's illness and subsequent change in patient care could be stressful for both patients and family caregiver, their mutual acceptance of having to live with the unexpected enabled them to limit distress for one another:

I suppose it's always just we're always waiting on results from hospitals that we're usually the most anxious. Each time it might gain or lose a bit, the cancer, it might be going a bit more in one certain area than the other, so that needs to be looked at all the time. So we do look at that differently. We're very strong minded... I suppose dealing with it, from the spiritual and mental point of view, we both go down that road. (Frank, P5)

Our whole lives have changed, both [patient] and myself and it took a while to adjust and accept. I think that's the big word, acceptance, and we mostly have learned to laugh at the situation and how things are ... You see there's always a way [of dealing with things] isn't there? Absolutely. Always a way. So, it really is every day is a different day. (Maggie, FCG10)

5.1.11 Having the same intention to support one another

Regardless of pre-morbid relationship status, severity of patients' symptoms or degrees distress of reported by patients or family caregivers, all participants agreed that the efforts of one another to simply cheer one another up had transformative effects on their wellbeing. For the most part, those who reported having had a close relationship with one another prior to the patient illness were better placed to know what could improve each other's mood, some with the use of humour and others through expressions of love and gratitude. When such small acts of support were perceived by both the patient and family caregiver to be intentionally helpful, they were then reciprocated between them. Mutual intention to support one another typically involved actively communicating with humour to one another. Section 5.1.11.1 explains the important role shared humour had for patients and family caregivers in their reciprocal support of one another.

5.1.11.1 Shared and intentional use of humour

As stated in chapter four, shared humour was a dimension of shared coping between patients and family caregivers. The use of humour by both patients and family caregivers facilitated mutual support between them because it could be used to diffuse tense situations or simply alleviate feelings of fear or worry:

When I'm down they [family caregiver] try to drag me out of it, they make me laugh, you know? They try bring up funny stuff, and you know... you know, try not, you know, take it serious, you know? (Neil, P7)

Of note, humour facilitated the introduction of difficult discussions between patients and family caregivers when they both might otherwise have felt unable to discuss without using humour. Indeed, humour was a communication tool used most effectively with individuals who reported that they did not like to take life too seriously and would typically attempt to skirt around more serious aspects of the palliative care experience. Here, humour between patients and family caregivers promoted open disclosure which enabled them to be supportive of one another:

Yeah, we always have a great laugh... We just get on so well with each other, it's amazing... I want them [family caregiver] to feel 'God I can talk to her, I could say anything to her' so that's great. I've always been like that, I'm so straight but like it works... it [humour] actually makes it more comfortable if you get me? (Louise, P6)

5.1.12 Intentional expressions of gratitude and reassurance toward one another

Facilitators of mutual support between patients and family caregiver were also the intentional expressions of love and gratitude demonstrated by both patients and family caregiver to each other. Intentional expressions of love manifested in both physical forms such as for example an embrace, but also in a non-physical form through simply acknowledging how mutually grateful they were for one another and how reassured they felt by one another:

I suppose when we're in bed at night, I listen for Maggie and she's all right and she's breathing and she's there with me, and that gives me great deal of solace, you know, because I know things are okay. There you go. I don't know if she listens for me or not! (Charlie, P10)

That's very nice to say that. Oh, my goodness. He [Charlie] never ceases to amaze me. We're 55 years married soon, and you know, that's a long time to be with somebody. (Maggie, FCG10)

5.1.13 COVID-19: Enabling mutual support between patients and family caregivers

The spread of COVID-19 caused multiple difficulties for patients and family caregivers, such as inability to receive visitors and friends, the anxiety caused by potentially contracting the virus, and the cancellation of patient and family caregiver support groups which might otherwise have been attended. However, some benefits also arose from COVID-19 which could facilitate mutual support between patients and family caregivers. Patients and family caregivers generally cocooned during COVID-19 which resulted in the family caregivers to stepping away from work commitments outside of caregiving. Cocooning also resulted in a reduction of their social interactions

outside the home which in some cases was a benefit when social visits were tiring for patients. Sections 5.1.13.1 and 5.1.13.2 explain how COVID-19 could on occasions facilitate supportive behaviours between patients and family caregivers.

5.1.13.1 Reducing visitors at home

Social support from friends and the wider community were appreciated by patients and family caregivers. However, both patients and family caregivers reported that visits by friends and the wider community was fatiguing for patients and results in increased distress for both the patient and family caregiver. Removing the risk of distress induced by frequent visitors enabled the patient and family caregiver attend more to one another and speak frankly about each other's needs. Moreover, receiving supportive communication over the phone still offered both patients and family caregivers the sense of being supported without the fatiguing nature of hosting guests:

Although we don't kind of impose and they're not ringing all the time, it's hard sometimes if he's [patient] sleeping or resting, they might just send a text or whatever, but that's a support as well. (Anna, FCG5)

5.1.13.2 Family caregivers working from home

Due to COVID-19, family caregivers were facilitated in their role as family caregivers in their ability to work from home in their formal occupation. Being able to work from home enabled them to attend to patients as needed. Patients placed importance on family caregivers being physically present and family caregivers were by choice or circumstance able to spend more time in-person with and comfort patients:

If anything, I suppose to a certain degree the COVID situation has given me a bit more time at home. So that's given me... a good opportunity to adjust with things and to be able to kind of, I'm back working full time pretty much at the moment, that adjustment has been a nice transition rather than everything

being thrown into the one pot and having to try manage four or five different things. (Eamonn, FG1)

Similarly, for patients, the COVID-19 pandemic has similar facilitatory effects on the ways in which they were able to support their family caregiver. With family caregivers being forced to remain at home, along with the non-caregiver population, the perception that they were required to remain at home solely to care for the patient was removed. This resulted in a unique situation where family caregivers were given an opportunity to reduce the amount of time they devoted to their paid employment and instead devote it to caregiving without much disruption to their career trajectories or social lives. This unexpected opportunity for the patient and family caregiver to remain at home together served to temper patients' views that they were burdening family caregivers and provided family caregivers with the opportunity to spend time with the patient:

I was originally working full time myself [in retail] ... And then obviously, then when COVID hit ... I'm full time now at home with him ever since ... You're getting to spend that precious time with him [patient]... without a doubt. The time that I have with my Dad is 100% precious to me. (Jen, FCG16)

The working from home has been a god send really. Silver linings, I suppose in COVID. There's very few of them. (Anne, FCG19)

5.2 Barriers to mutual support between patients and family caregivers

5.2.1 Conflict between patient and family caregiver

A key barrier to mutual support between patients and family caregivers was the presence of discordance within patient and family caregiver relationships. The experience of palliative care could also be distressing for patients and family caregivers and in some cases, exacerbated anxiety and fear for both patients and family caregivers. The presence of such emotions could also cause conflict between the patient and family caregiver. Discordance and resentment were more common when patients and family caregivers who reported prior conflict (i.e., before the patient's

illness). In these cases, patients resented being cared for and tended not to report expressing gratitude or love to their family caregivers. Family caregivers who reported receiving no thanks for their efforts felt more strained than other family caregivers who did not report conflict between them and their person they cared for. Sections 5.2.1.1 and 5.2.1.2 explain key dimensions to conflict between patients and family caregivers and its impact on supportive relationships between them.

5.2.1.1 Conflict in relationship prior to patient illness

A difficult relationship between the patient and family caregiver prior to the patient's illness was a barrier to mutual support between patient and family caregivers. Patients and family caregivers who reported conflict between one another prior to the patient's illness reported that they found it difficult to adjust to challenging circumstances. In some cases, family caregivers found it strained them to have to put aside existing resentment to be committed as a family caregiver to their ill family member:

She [patient] always has been like... quite a difficult person to live with over the years, and you know, she has... she's quite... it's kind of hard to explain to a stranger who doesn't know her, but she is a really, really selfish person... a self-orientated person. (Craig, FCG21)

Pre-existing conflict was particularly difficult for both patients and family caregivers when it came to caregiving tasks that could trigger concerns around loss of dignity for the patient such as the need to be assisted in self-care. Patients in these instances attempted to protect their dignity by claiming that they did not need the assistance provided by family caregivers or by micro-managing family caregivers in their care tasks. This occurred most often in patient and family caregiver relationships where the patient was the parent of the adult-child family caregiver and the patient and family caregiver differed in gender, such as in the case of patient who was a father and his daughter his family caregiver, or a patient who was a mother and her son her family caregiver:

I'm a very stubborn person. But I know she's [family caregiver] wound up about the whole thing and unless she was there [at healthcare meetings], she wouldn't be happy. So I let her go along ... At the moment it's more for her than me. Because as I say she's uptight ... like she's stubborn too. She wants to be in control of everything. (Tom, P14)

She would kind of come across as being a micromanager ... where her input actually isn't... well, it's, it's rude to say it's not warranted, but being told while you're in the middle of doing something to do, like, a tiny variation of the same thing that you're about to do differently is kind of annoying, but I absorb it. (Craig, FCG21)

The lack of closeness and intimacy between some patients and family caregivers made open communication difficult for both the patient and family caregiver. In such situations, participants reported difficulty disclosing information to one another which in turn made them feel vulnerable in their relationship with one another. Craig (FCG21), who reported conflict between him and his mother who he cared for communicated:

She's [patient] horrified by the idea of having to use a commode because then somebody has to deal with, you know, emptying and cleaning the commode, and she's just horrified by that. So, she would do nearly anything rather than use that. So that has never been used even though it's here. It's never been used. That kind of thing I would find difficult to deal with. If it was necessary, if it was absolutely necessary, I'd have... I would just deal with it, but she would find it more abhorrent than me, I think. (Craig, FCG21)

5.2.1.2 Change in patient behaviour

In some cases, medications caused substantial change in the patient's personalities, resulting in a new relationship dynamic between the patient and family caregiver. Patients who were once perceived by family caregivers to be patient and kind were now perceived by family caregivers as a source of irritation and annoyance:

It's really the mood swings as well and like he'll [patient] say something to me. And then he'll say, 'I'm sorry, I didn't mean that'. You know what I'm saying? And I'll say, 'Don't worry about it, relax, you're okay'. He's snappy and sometimes when I come up in the evening times to watch my own bit of telly, I take a sigh of relief. And that's being... I'm being totally honest with you.
(Teresa, FCG3)

Family caregivers held a self-imposed expectation that as 'good caregivers' they should let these behaviours go without conflict and have more patience with the patient. However, being expected to allow for patient challenging behaviour was difficult for some family caregivers who had generally been able to navigate arguments on an equal footing prior to the patient's illness. In a few cases, family caregivers reported that they were scolded by argumentative patients and perceived that they were expected not to retaliate. This expectation that patients were 'allowed' to berate or complain to family caregivers without family caregiver retaliation placed strain on their relationship. This was obvious in the case of patient James (P8) and his spouse and family caregiver Tina (FCG8):

He [patient] has a very short fuse. And sometimes the person that you're close to is the person that you can be kind of a little bit short with sometimes. ... And, he didn't suddenly become an angel. He's just the same as he always was. Short fuse, if you drop something on the floor or whatever. So that's the way it is like.
(Tina, FCG8)

In situations where family caregivers felt patients were at risk due to their cognitive deterioration, family caregivers felt restricted by their caregiving role. Some family caregivers who provided care to patients with cognitive impairment reported anxiety because they felt less able to complete their own self-care and other daily tasks. Overall, a deterioration in patient cognitive ability restricted supportive relations between patients and family caregiver because both the patient and family caregiver capacity to support one another was undermined.

5.2.2 Conflict within the wider family unit

As discussed, a terminal diagnosis for the patient elevated distress for the wider family and caused fear and anxiety for the family. Families with pre-existing tension were at risk of relationship breakdown with their new additional tension exacerbating their distress. In cases where patients and family caregivers reported the absence of conflict before the patient illness, these patients and family caregivers reported that it was somewhat manageable to address and conflict which has arisen since the onset of the patient illness. However, in either case, participants reported that conflict within the wider family because of the patient's advancing illness was challenging:

At the start of this [patient diagnosis] when everyone was so tetchy, there was a couple of things that I wasn't ready for. [Daughter 1] was like 'you tell everything to her [daughter 2] but you never include me'. We had a whole day of that and it turned out to be nothing apart from the fact that she was so upset. The truth, was after a day of upset, it turns out I didn't mean any of that and I know it's not true and I shouldn't have said that. (Tina, FCG8)

Patients and family caregivers reported that conflict could manifest in their wider family in situations where this was a lack of support available to the patient and family caregiver from the wider family, when the family caregiver was reluctant to ask other members of the family for support, and when the family caregiver struggled in meeting the needs of both the patient and other members of the family. The contexts and consequences of familial conflict on the patient and family caregiver relationship are outlined in the following sections 5.2.2.1 to 5.2.2.4.

5.2.2.1 Lack of support from the wider family

In contrast to those who opted into the family caregiver role and found contentment in their choice, family caregivers who felt forced into the role reported feeling trapped and isolated. These family caregivers struggled with the workload, feeling that their efforts benefited other member of the family those who they perceived had abandoned them in their caregiver role. This resentment was intensified during

periods where family caregivers needed time to recuperate from burnout but were not offered the support, despite these family caregivers alleviating their other family members' worries about the patient. In some cases, this served to impact negatively on supportive behaviours between the patient and family caregiver because the impact of caring on the family was borne primarily by the family caregiver as opposed to other family members:

They do very little. I could ring and ask them... one brother will drop down twice a week just to check in. The other brother is very caught up in his own life. So, he wouldn't have as much time or as much empathy either. (Pauline, FCG14)

Of note, some family caregivers who self-identified themselves as the primary family caregiver felt that their caregiving efforts for the patient had an unintentional side effect of freeing other family members of their responsibilities:

I couldn't expect the brothers to come up and move in here for a week while I was away. I never asked them. I just assumed that they wouldn't... well that they couldn't, wouldn't, whatever ... Put it that way. So I made that decision to not go away [for a break] for [my father]. (Frances, P9)

5.2.2.2 Family caregiver reluctance to ask for family support

Some family caregivers were reluctant to ask other family members for support in their caregiving role. Family caregiver reluctance to ask the wider family for support tended to manifest in families where the sole female (adult) child was the primary family caregiver in a family of male siblings. This occurred primarily because of the primary family caregivers' lack of faith in other family members to care for the patient to the standard required or the perception that other family members had more 'important' careers which they needed to focus on. Other family caregivers felt too proud or burdensome to ask other family members for assistance due to their perception that their request would be refused. When family caregivers felt that their pleas to other family members would be futile, they reported that they did not reach out to other family members to assist them in their caregiving role. This could lead to family caregiver burnout and adversely impacted on mutual support between patients

and family caregivers in the context that family caregivers felt they had then less capacity to provide support to the patient:

First thing in the morning, he's normally up before me, and he's downstairs, because I really wake up some mornings and I don't want to go down. You know, because I'm saying what am I facing this morning. (Teresa, FCG3)

5.2.2.3 Family caregiver struggle between patient and other family member needs

Family caregivers who also had other family members depending on them found the division of their caregiving duties to be difficult. These family caregivers communicated that they were experiencing guilt no matter who they were providing care to at that time because they felt that they were intermittently letting down both their dependants and their ill family member. Struggling between the needs of the patient and their other family member made family caregivers feel less able to provide the amount of care they felt was required by the patient:

She [patient] knows like I'm at home, all my children – well they're adults now but all my family still live at home. I've two children and we all live at home. Well one actually doesn't, she's after moving out now, and now I have a new granddaughter as well so I'm trying to spend time with her as well. It's very difficult and stressful. (Rebecca, FCG18)

Attending to both the needs of the patient and their other dependants was particularly difficult for family caregivers who assumed caregiving duties for other members of the family on behalf of the patient. The patient's inability to provide support to the family caregiver in addition to the vacuum of support left by the patient by being unable to care for their own dependants, required the family caregiver to provide a care to both the patient and the patient's dependants.

I'm a sister to my sister, but I have taken on the parental role, like looking after her. (Isabella, FCG7)

5.2.2.4 Differing opinions within the family regarding patient care

A less frequent reported but still significant barrier to mutual support between patients and family caregivers was the discordance in preferences within the wider family unit. Differing opinions among family members on the 'correct' care plan for patients or how family caregiving should be performed caused in some cases, conflict for the family in question:

[One family member] might have a belief down one road and one might have a belief on a different road and there's always a danger that one might have more faith than the other, and it could clash and it almost [did]. (Frank, P5)

Differences in preferences for care ranged across multiple dimensions of formal healthcare including for example, decision-making in relation to the medical management of the patient's pain, but also in relation to the validity of research into COVID-19 and in particular the uptake of vaccination for the family members who were not providing direct care. Such conflict caused anxiety for both the patient and family caregiver which impeded their ability to focus on supporting each other. This was particularly the case when the patient and family caregiver felt not only unsupported by other family members and when there was conflict within the wider family. Conflict within the wider family was exacerbated in cases when members of the wider family refused the COVID-19 vaccination and engaged in practices that breached COVID-19 national lockdowns, potentially putting the patient at risk:

I have another sister, she kind of hops from one house to another house all the time and then when you talk to her about the COVID, and you say you can't be doing that... I have a brother about three weeks ago had a chest infection. And she went, and I mean he told her he didn't feel well and that he'd picked up a bit of a bug. She still went down to his house and then came to me on the Monday, and I found out about this on the Wednesday. And I said 'what are you doing?' And I said 'you don't have to have COVID you know, you can carry it. (Stephen, P15)

5.2.3 Family caregiver burnout

5.2.3.1 Limited family caregiver self-preservation

When family caregivers could not find the time for self-care behaviours such as leisure activities, pursuit of their own interests and hobbies, or even relaxation, this had negative repercussions for the patient and family caregiver relationship. Family caregivers experiencing burnout often felt more irritable, lacked energy, and experienced emotional numbness which acted as a barrier to both intuitive care and to providing emotional support to the patient. Whilst these family caregivers strove to give physical support during such periods of care, they found that they had less patience for the patient and decreased motivation as a caregiver, and even in some cases, less positive experiences with the person they cared for:

I can't think of anything that we would have actually done differently to or that we would do differently to support her or to... you know, provide her with assistance... all the various assistances that we have. I would probably say that we do it with slightly less of a... I can't quite think of the phrase... with less joy in our hearts maybe is the kind of thing I'm trying to say. (Craig, FCG21)

5.2.3.2 Family caregivers prioritising patient care over their own wellbeing

The main cause for a lack of self-care behaviours in family caregivers was their prioritisation of the patient's needs over their own needs. Family caregivers were acutely aware that time left with their loved one was limited and hence felt they should devote all of their energy to their caregiving role:

It would be just her needs I suppose, I wouldn't have been thinking of myself at all to be honest, and I know sometimes I'm feeling pressure and stress and sometimes I probably should take a bit more of a break or a step back, but I just end up feeling worse. I just feel I need to be here for her all the time as much as I can, every moment, because I don't know how many more moments I'm going to have with her, so I just have to do it. (Sarah, FCG4)

However, the cognitive dissonance family caregivers experienced between knowing that better self-care would benefit them and yet remaining being reluctant to reduce the level of care they provided to the patient, limited them in providing emotional support to the patient because their own emotional needs were not being met.

5.2.3.3 Family caregiver reluctance to be apart from patient

Another factor which impeded family caregivers to take part in self-care behaviours was their reluctance to spend time apart from the patient. This was caused by both their own and the patient's expressed anxieties about spending time away from their primary family caregiver. Family caregivers' anxiety when apart was triggered by worry that the patient would have an accident such as a fall in their absence, a lack of faith in others' ability to provide care, and their own feelings of guilt that arose for them when they attempted in briefly prioritising their own needs over their caregiving role:

There's times when I'm going [to work] in the morning... like I'll only be gone a few minutes and [my daughter] will be here and he'll say 'Okay, I'm fine, I'm grand.'... It's just, I just hate kind of leaving him [patient]... I'm always afraid what if he falls because he's not great on his legs, what if he falls? (Anna, FCG5)

In some cases, patients themselves undermined relations between them and their family caregiver when they refused to allow the family caregiver to spend time away from them. This interaction often frustrated family caregivers leading to feelings of resentment towards the person they care for:

It can be tough, but... I hate complaining, you just have to get on with it... She wants me for everything, to go into the toilet, to wash 'I'll wait on Sarah'. The carers were here the other day, and I just flew over to Tesco [shopping centre], more to get out of the house to be honest... But the carer said to me 'Sarah, I think she wants to go to the toilet, I'm after asking her a hundred times and she says no, no'... the minute they go out the door she says, 'Sarah, I have to go to the toilet, I'm bursting' and I said, 'Mam why didn't you ask them?' She was saying 'No, no, I wouldn't ask them.' (Sarah, FCG4)

Overall, over-reliance of patients on family caregivers and family caregiver prioritisation of patients over their own needs could result in family caregivers themselves feeling unsupported by the patient.

5.2.4 Patient and family caregiver difficulty accepting change to their respective roles

Patients and family caregivers who had 'swapped' caregiving roles found the adjustment to the uptake of their new role more difficult. This was particularly difficult for some patients who had once acted as a caregiver to their own children and who were now recipients of care from their adult children:

That decision will be just mine completely, they're not going to look after me, no way, and that would be final. I told that to the nurse that there's no way they would be changing me they would be doing something like that. I wouldn't be able to cope with that. I just would prefer them to come in and visit me.

(Louise, P6)

Whilst some patients who were parents found it difficult to accept care from their adult children, the same adult children were generally comfortable in their roles and content to repay the debt of care they perceived was owed to their parent. This was particularly the case for family caregivers who were adult children and who were supported by other family members. However, patient and family caregiver difficulty accepting change in role were not just dependent on the historical context of caregiving relations within families, but also on whether the patient had been the breadwinner on whom the family caregiver was previously financially dependent upon. For example, in some cases, families' financial situation worsened because of income loss associated with the patient's illness and/or the family caregiver's use of unpaid leave from/cessation of their employment to care for the patient. In these situations, family caregivers often felt torn between having to provide for the wider family and care for the patient:

The only thing is - and it's so annoying - but you have to worry about the finance of the whole house and stuff like that. That's the only thing that's really

annoying when someone has cancer, there should be help out there like, because obviously my Mam's not working, and we have a mortgage and she's a single parent. (Kelly, FCG6)

In such contexts, patients struggled with having to resign themselves to being cared for rather than care for others in their families. Where once they were both financial providers and household organisers, they now felt they were a burden on their family caregiver.

5.2.5 Burden associated with change in patient illness

Patients and family caregivers reported spending much of the early stages of palliative care in a monotonous routine. A significant barrier to mutual support between patients and family caregivers was the restlessness and boredom caused by the monotony of life events. That said, family caregivers perceived that attempts to break the monotony with a positive experience was often derailed by what were acute changes in the patient's illness:

Every day is exactly the same... [but] every time I've tried to make that different, I've thought he's actually not that bad. I think we booked two nights away or whatever. Always cancelled, everything's booked, cancelled, booked. [Plans have been] cancelled for absolutely everything. So, it's not possible [to share positive experiences] really. And you can always try and fool yourself that it's not good at the moment, but we'll do it in two weeks or whatever. That's not happening. It's just not happening. (Tina, FCG8)

Moreover, change in the status of the patient's illness could impact adversely on supportive relations between patients and family caregivers because of the strain that manifested between the patient and family caregiver in these situations:

You can feel the strain... there's kind of a strain there ... I've done my best for him right up till the very end ... you don't have 100% of your own life. (Jen, FCG16)

5.2.6 Mutual anticipatory grief between patients and family caregivers

A key obstacle to mutual support between patients and family caregivers was anticipatory grief related distress for both patients and family caregivers. Whilst the patient's death would result in different outcomes for the patients and family caregivers, both were still experiencing the loss of one another. The sense of urgency in creating positive and sentimental experiences before the patient's death somewhat tarnished the intended events, with the thought of the patient's death hindering their shared enjoyment. Family caregivers' wish for all events in the patient's remaining life to be without fault inadvertently placed pressure on both family caregivers and patients to behave in ways that were unnatural to them, attempting to hide physical pain and emotional distress for each other. Thoughts that patients had about their own deaths were particularly upsetting to family caregivers who often felt they could not express their thoughts about the patient's death to the patient. In this context, fear of their impending loss restricted mutual support between patients and family caregivers:

I think we're grieving already for each other and have been doing for a while, and you're sitting there talking to her and Michelle's saying I don't to be in a box, I don't want to die, I don't want to leave. So, the most difficult is contemplating the fact that she's going to die. By a mile that's the most difficult. People say to just take day at a time, day at a time, it's impossible to look down the road whenever that is. (Brian, FCG11)

5.2.7 Family caregiver feeling under-appreciated by patient

As already outlined, family caregivers provided physical support to patients and which patients often found difficult to reciprocate due to their illness-related disability. Often patients attempted to reciprocate these acts of expressions of appreciation and gratitude. However, in some cases, patients did not reciprocate family caregivers' efforts with gratitude or encouragement, and to which family caregivers felt minimised the sacrifice they were making in their own lives to care for the patient:

Things only matter to her... things are only important for her when they matter to her world. And so, she's become even more kind of self-orientated you know, over the last few years, and particularly over the last three months or whatever... She doesn't do praise, she does complaining. (Craig, FCG21)

In situations where family caregivers felt their efforts were not appreciated by the patient, family caregivers indicated that this was the case no matter how much time or energy they gave to their caregiving role.

5.2.8 Disruption due to COVID-19

As already reported, many patients and family caregivers felt isolated and in fear because of the disruption to healthcare services caused by COVID-19. Both patients and family caregivers were reluctant to access emergency care given the likely limited access they would have had to each other should the patient be admitted to hospital care. The fear of such events caused distress for both patients and family caregivers, particularly with regards to the possibility of the patient being in isolation without visitors due to COVID-19 restrictions. In these cases, mutual support between the patient and family caregiver could be restricted because of the physical separation the patient's admission to hospital or a hospice facility would inevitably result in:

He ended up spending nearly a month in hospital so that was so hard... so hard because they wouldn't let me in. And then it was appointment only, and then they were messing up his tablets, and then he had a fall in there, and then he was hallucinating, and... No, I want him home. That's it, where I can make sure he's okay. (Frances, FCG9)

The manner in which some patients and family caregivers received the diagnosis given the restrictions of the COVID-19 pandemic was difficult for some patients and family caregivers. Often the patient received their diagnosis of advanced illness when they were alone in hospital and without any visitors permitted. Patients then found themselves having to disseminate this news to their family members through a series of phone calls. This caused significant distress to patients and family caregivers, both of whom had previously relied on each other when previously facing upsetting

circumstances in their lives. Processing this news alone without each other was often traumatising for patients and family caregivers and restricted their ability to sufficiently support one another in these situations:

I'm here [at home] and he [patient] rings me, and then he rings each of the girls, and they are all separate [in separate places]. So, we never got an opportunity to be told where we were together... It was just such a shock to everybody... We were all in different states of shock and upset and in different places. All of that, was so hard to deal with. And it keeps it keeps coming up [traumatically] if you know what I mean. I just think if people have to get news like that, that it's very, very important that at some point that the hospitals as part of as a policy, don't give that information to people the way we got it.

(Tina, FCG8)

The inability of both patients and family caregivers to provide support to one another in these instances caused distress to both the patient and family caregiver. Moreover, patients and family caregivers also felt distress and guilt due to their respective other being alone on receipt of such information:

I'm married with five children. I was in hospital... when I was in the hospital and diagnosed, we had COVID of course, so I had to tell them [wife and children] over the phone, which was very difficult to tell them that I had the cancer, and a particularly aggressive cancer at that. So, it was a hard thing to do over the phone. (Frank, P5)

Beyond the healthcare context, COVID-19 impeded patients and family caregivers experiencing relationship enhancing experiences such as holidays, family outings, and celebrating birthdays and Christmas. On multiple occasions, family caregivers' planned activities which were intended to be supportive for patients were cancelled due to COVID-19 lockdowns and restrictions:

You know there's challenges, with COVID now I can't really go anywhere.

(Stephen, P15)

Such restrictions manifested in some patients and family caregivers a sense of hopelessness. Patients and family caregivers felt that they were no longer able to share in positive memory-making activities together which was distressing to both parties due to their limited time remaining together.

5.3 Chapter conclusion

This chapter has outlined factors that facilitate and/or restrict mutual support between patients and family caregivers in palliative care. The findings presented in this chapter suggest that the presence of external support, such as healthcare services and the wider family, can impact on a patient's and a family caregiver's capacity to provide support to and receive support from one another. Support from the wider family and from palliative care services enhanced patients' and family caregivers' propensity and ability to provide support to one another. Support from other members of the family provided respite for family caregivers in addition to emotional support to both patients and family caregivers. Support from palliative care services assisted the patient and family caregiver to disclose their concerns to one another which in turn helped alleviate patient and caregiver mutual distress and increase both patient and family caregiver capacity to support one another. The absence of support from the wider family made it more challenging for patients and family caregivers to be mutually supportive.

Mutual support between patients and family caregivers was fundamentally shaped by pre-existing relationships between patients and family caregivers. For the most part, patients' advancing illness impacted adversely on the physical and emotional wellbeing of both the patient and family caregiver. Both patients and family caregivers also encountered changing roles, often without choice, and were challenged in the process of adapting to different roles be it care recipient or caregiver. Nevertheless, having already had a supportive relationship with one another helped patients and family caregivers collectively adapt to living with the challenges associated with life-limiting illness. An already existing supportive relationship between the patient and family caregiver was a key condition for both the patient and family caregiver to

express gratitude to one another and return acts of care and support to each other intended to alleviate burden for each other.

In cases of already strong supportive relationships between patients and family caregivers, the family caregiver valued the patient's appreciation of them. However, if the relationship between the patient and family caregiver was one of conflict and tension before the patient illness, the family caregiver tended to pay less heed to expressions of gratitude from the patient for their support. In turn, without value being placed by the family caregiver on this form of patient support, resentment on part of both the patient and family caregiver was prevalent and mutual support between the patient and family caregiver was restricted. Distress for both the patient and family caregiver could be exacerbated by pre-existing conflict within the wider family and by the primary family caregiver receiving little or no support from the wider family.

Importantly, the ability to choose whether or not to assume a caregiving role was central to how supportive the family caregiver felt they could be to the patient. Family caregivers who felt that they were being forced into the role of caregiver and/or when they felt their caregiving role enabled inadvertently other family members to shirk their responsibilities to the patient, were more likely to be resentful and more distressed in caregiver role when compared to those who felt less restricted in their caregiving role. A key finding from this chapter is that mutual support between the patient and family caregiver was shaped by patient and family caregiver perceptions surrounding both freedom and constraint. Hence, it is important to consider how patient and family caregiver mutual support in palliative care operates in the context of their decision-making for palliative care. The next chapter (chapter six) outlines how mutual support between patients and family caregivers in palliative impacts on patient and family caregiver decision-making in palliative care.

Chapter 6: Decision-Making in Palliative Care for Patients and Family Caregivers in the Context of Mutual Support

Chapter 6: Decision-making in palliative care for patients and family caregivers in the context of mutual support

Patients were for the most part pivotal to all decisions made about their own care. Patients had to consent to any changes in their treatment or care. Decisions were made with the assistance of their family caregiver and external family members in most cases, but occasionally a strong-willed, self-described 'stubborn' patient would decide against involving anyone else in their care decisions. The degree to which patients involved family caregivers in the decision-making process for care varied. Some patients made decisions entirely on their own (n=3) whilst others listened to the family caregiver to allow the family caregiver to feel part of the decision-making process but ultimately reverted to their own decision (n=4). The remainder of patients heeded to family caregiver input and made decisions that the family concurred with and/or handed over decision-making almost entirely to family caregivers at dependent on illness severity at time of decision-making (n=8). Patient and family caregiver navigation of decision-making in relation to care and in the context of attempting to support one another is outlined in the following sections of 6.1 to 6.12.2.

6.1 Patient and family caregiver perceived responsibility in the context of family role

Previously held identities and roles influenced decision-making processes for patients and family caregivers. Traditional family roles as well as roles specific to traditional gender norms within the family appeared to dictate their behaviours. This was prevalent for example in cases where the patient who was a father to their family caregiver remained stoic about their own preferences and decisions for care. For instance, self-described 'stubborn' patients in the study were men with non-dependant adult daughters acting as family caregivers. Such patients found it difficult to adjust to being supported and cared for and whilst daughters acting as family caregivers prioritised dignity retention more so than any other type of family caregiver, their father's uptake of their new care recipient role was emotionally distressing for both the patient and family caregiver. Family caregivers who were daughters attending to their father's care were particularly careful to retain some elements of their (i.e., patient) previous roles to enable their father to feel secure in

their fatherly role. For older men with their daughter acting as their family caregivers, the family caregiver willingness to accommodate their father's preference underpinned how these family caregivers delivered care and gave support to their ill family members:

His independence was a major thing to him, so there were little things around the home that he would have always been able to do for himself. Now, obviously, he can't, and he's feeling that now. So obviously, he's relying on me to do all these little things for him. He would have been a man obviously that was out and about all the time. He's done his own little things, had his own little routine, and now that all of that has gone, he's finding that extremely difficult, like it's a major thing for him. (Jen, FCG16)

Women participants who were patients tended to seek the views of their family caregiver and wider family regarding their end of life and ordinarily attempted to gauge their family's consensus on an issue before they made a decision about their care. This was particularly the case for women patients who had children, whether their children were adult children or dependants. This was due to these women having acted as household counsellors in their mothering role and continued to act in a maternal and caring way even with respect to choices around their own death. This contrasted with the traditional fatherly role of making decisions 'for' the family. Male patients who were parents of their adult-child caregiver tended to accept support from their caregiver in terms of information gathering and communicating with healthcare professionals, but could still make decisions based on their own preferences for care:

He [patient] would be a little closed off [emotionally] throughout this journey I suppose... what he appreciates the most would be to keep everything normal, and not to look at him with pity or sadness, to treat him as a human being not as a cancer patient, or as someone who's dying ... it's 100% what he wants. (Pauline, FCG14)

In general, family caregivers were motivated in their role as an advocate for the patient and wanted to honour the patient's wishes as best as possible. Whilst family

caregivers expressed clarity with respect to their own wishes for the person they cared for, they did not necessarily verbalise their preferences for fear they might place pressure on the patient to make decisions based on the family caregiver's and other family members' preferences. Family caregivers sought to carefully balance the task of supporting the patient to make their own decisions about care against their need to ensure that the patient was making decisions based on what the family caregiver viewed as appropriate:

I suppose any of the suggestions that have been put to us or any changes that, you know, upcoming medical appointments and things like that, there would always be some sort of dialogue between us about it and then I'd always say, 'What, you know, how do you feel about it?' At the end of the day, it's my role to respect exactly how she [patient] wants to go about things as well. I can't say 'well I think you should do this' if she doesn't want to do it at the end of the day. We can talk about it and maybe I'd have a little bit more of a voice on certain things, by all means, but certainly it is down to make a joint decision but at the end of the day as I say I have to support and I have to respect the decisions that she wants to make. (Eamonn, FCG1)

Some family caregivers became frustrated if other family members voiced opinions contrary to the patient's wishes, particularly if this caused conflict between the patient or family caregiver and a member of the wider family. Patients and family caregivers attempted to reduce conflict and the risk of stress to one another as much as possible, whether between themselves or within the wider family unit. This aversion to conflict was important for participants and in many cases, participants included other members of the family in decision-making about care to avoid conflict:

I can see the signs [of family argument] and it didn't come to that ... what I done was I put them all together ... Just to take the family, family unit, treat the family unit right and the rest will work out. (Frank, P5)

6.2 Judging quality of time over quantity of time for each other

Issues frequently discussed between the patient and family caregiver in relation to treatment and care were those which covered balancing between the enhancement of

the quality of the patient's remaining life and the potential for the patient to live longer through life-prolonging treatments. The majority of family caregivers supported their respective other in whatever decision they wished to make even if patients made family-focused decision for the benefit of the wider family. However, family caregivers also encouraged patients to attempt to make more patient-focused decisions even if those decisions could be difficult for both the family caregivers and wider family:

He [patient] considers how it's going to affect us when he goes make a certain decision ... but if he's going to be in a lot of pain, I wouldn't want to see him in pain just for the sake of staying [living] longer. (Isabella, FCG7)

Patients often reciprocated in their support to the family caregiver by allowing family caregivers to feel heard in the decision-making process even if the patient felt that their own preferences for care would alleviate the family caregiver's suffering more so than the family caregiver's preferences for the patient's care. Indeed, some patients heavily involved their family caregiver in decision-making to alleviate their sense of guilt for the distress caused to their family because of their illness or simply because they felt family caregivers had educated themselves more regarding their treatment options than they themselves had:

He's [family caregiver] educated himself with regards to it [my condition]. So, I haven't really educated myself, I've more or less been dealing with it... with the pain, with the day-to-day thing... where Eamonn has really, really gone into this with his heart and soul and educated himself on the whole process. (Irene, P1)

Both patients' and family caregivers' decision-making behaviours were influenced by their perception of the effects of medications on the patient. Central to this was the discussion around quality versus quantity of the patient's remaining life. If the patient felt that the medication was causing side effects that were more difficult to bear than the symptoms they were prescribed to treat, patients were generally supported by family caregivers and the wider family to change or cease their treatment:

I said I would try it [opioid medications] and it was so uncomfortable then I said I would stop, so that's what I'm doing. And they all [family] said 'That's up to you, if you want to stop, we'll back you.' (Tom, P14)

It was understood by family caregivers in these cases of severe symptom severity, that while the support of family caregivers was appreciated by patients, it would not ultimately affect the patient's decision because of the acute discomfort the patient in question was in. Tom (P14) clarified his decision-making in this context:

My mouth's hurting me all the time, I can't do anything with it, and I can't even enjoy my food, so I have to stop this thing now... The type of person I am if I want to stop, I stop and that's it. As I said, I'm stubborn. (Tom, P14)

6.3 Patients accepting treatment for the sake of family caregiver and dependants

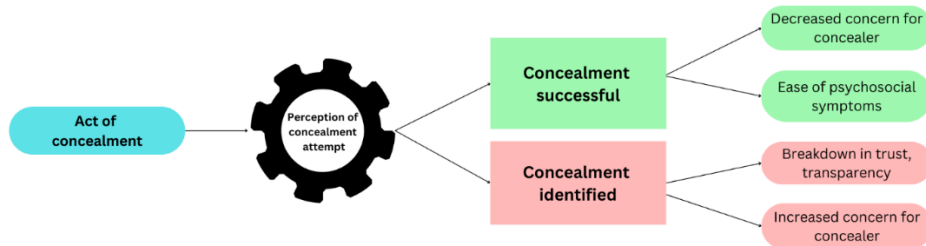
Patient participants generally involved their family caregiver in decision-making for aggressive treatments:

We [patient and family caregiver] make them [decisions] together and we always say look, try it out, because she [patient] doesn't want me to die ... When I was on the chemo, and I found out that the cancer was still kind of growing ... the doctor told me that it [tumour] was growing again. So, I decided to come off the chemo after eight months. I took a break away from it for about two months. And then I decided to try the new treatment that they were giving. And that was a decision made from me and [family caregiver]. (Stephen, P15)

Some patient participants had previously been diagnosed with cancer and had already endured the effects of radiation and chemotherapy. In some cases, these patients were motivated to take these treatments to give their wider family the decision outcome the family would want even if they felt it was to their own detriment. Indeed, patients with young dependants were willing to receive any treatment which might increase the period of their remaining life regardless of the severity of the side effects of such treatment. These patients were motivated by acute fear about the future of their dependants after their death. Their attempts to 'buy time' by undertaking intensive courses of life-prolonging treatments were often supported by their dependants and family caregivers and helped by the patient's successful concealment of their symptoms. However, if these symptoms were not concealed successfully and the true side effects of treatments were observed by family caregivers, the family

caregiver could attempt to prompt the patient to reconsider whether the symptoms were worth the additional time. This process is outlined in figure 7 below.

Figure 7. *The effect of successful or detected concealment*



This self-sacrifice for the sake of others was in some cases, a point of contention between the patient and family caregiver as shown here by Neil (P7) and his daughter Isabella (FCG7):

If I had a choice and offered the more aggressive treatment and spend more time with [family caregiver], absolutely [I would] take more aggressive treatment. (Neil, P7)

He cares about us a lot. So, he knows the impact he will have. He definitely takes that into consideration when making decisions. And I think that's why he asked for input as well ... I know it's a balance of like, a good quality of life for a shorter time or it could be horrible quality of life for a longer period of time. (Isabella, FCG7)

That said, occasionally if a patient had already felt influenced to take treatments which had some potential to be curative at the time of taking the treatment by their family caregivers, they did not allow themselves to be influenced again by their family caregivers. Indeed, some patients reported their frustration at being given advice by family members not experiencing the severe pain that they were experiencing, perceiving that should these individuals ever experience the same degree of symptom severity, their advice would be different:

That's what I would base my decisions on, what I'm going through, not what other people tell me. (Tom, P14)

The role of concealment in decision-making was influential on decisions made, and the standpoint from which patients and family caregivers felt they were making decisions. Concealment was impactful as it altered the decisions made between patients and family caregivers who, despite potentially having distress deescalated as a result, did not have the full picture of what was occurring for their counterpart. Concealment was enacted in both explicit and implicit ways, explicitly in the form of verbal untruths or understatements, and implicitly in patients altering their physical appearance to 'appear' well, as will be discussed in the next section (6.4).

6.4 Patients disguising change in their physical appearance for the benefit of family caregiver

For some patients, the detrimental effects that their illness or treatments had on their physical appearance caused them acute distress. Attempting to look well for others was present throughout many of the patients' interviews in both men and women of varying ages and with both young and adult families. It appeared that this decision was made by the patients to hide their appearance of being ill and was particularly prevalent in patients who wanted to deflect attention away from their illness for the sake of the family caregiver. The change in patient appearance influenced decision-making as patients who were successfully concealing the effects of their illness and treatment by not revealing their true pain, fatigue or weakness were now unable to conceal the effects of the treatments on their outward appearance. The effects of the belief or disbelief of the masking of physical symptoms followed the same process of explicit concealment, which is illustrated in figure 7 (pg. 159). Patients frequently mentioned the distress caused by their own physical appearance following a dramatic weight loss:

When I look at myself in the mirror and I was thirteen and a half stone and I'm down to eight and a half stone, well I was down to eight and half stone, I just want to run away from myself. (Stephen, P15)

Patients made the decision to appear well for the benefit of their family caregiver. While family caregivers were often appreciative of the patient's efforts to maintain the normality of their previous appearance, family caregivers felt worried that the patient's attempted 'healthy' looking appearance would cause issues in misleading other family members and healthcare professionals. Family caregivers that were unconvinced by patients' attempts to conceal often acted as advocates for the patient in the lead-up to decision-making processes with healthcare professionals to ensure that healthcare professionals understood the gravity of the patient's condition:

She never... she never really looks sick, when you think of someone who has cancer, you think that they're going to be like, really ill looking. She still looks amazing. She still gets up, does her hair, her makeup ... no matter how sick she is. She does always look so well. So, I think it's very hard if someone's looking at her looking so well, they're like, 'Oh, no it must be just in her head'. Or 'You look so well, so how are you sick?' ... [so] I talk about my Mam [to wider family and palliative care team] being sick or having a bad day. (Kelly, FCG6)

Dependent on the intention of the support, patients and family caregivers could deem support in this context as masking and concealing symptoms and distress to allow their counterpart flexibility in their contribution to decision-making processes, or conversely, ceasing their concealments to allow their counterpart to make a decision when provided with all information pertaining to the reality of their shared circumstances.

6.5 Family caregivers valuing the patient's first-hand experience of their illness

Family caregivers considered patients to be experts about their own symptoms, particularly with regards to the patient's ability to cope with pain until deciding to medicate for it and when their symptoms were deemed too severe by the patient to cope with without treatment to best manage their symptoms. Family caregivers recognised that they could not experience the degree of symptom severity first hand and therefore heeded patients' reports of their own illness and respected the wishes of the patient in terms of how to manage their symptoms. However, some patients felt that their family caregiver could not possibly understand the severity of their illness and therefore might not seek advice from their family caregiver:

It's me that's going through it. Nobody knows what I'm going through in the end. (Tom, P14)

Patients' bodily experience of both symptom severity and of the side effects of their treatments were influential on their decisions to continue or cease certain treatments. Patients' decision to end severely painful or nauseating treatments were therefore often made hastily whereby the patient called an abrupt halt to a treatment due to their inability to endure its effects any longer. The decision to cease a treatment was made in two distinct ways. The decision was sometimes made with the family caregiver earlier in the treatment phase when the effects of treatment were beginning to cause distress for the patient:

There was a double dose [mediation] I had to get and then all of a sudden, with my mouth I couldn't taste, it was on fire all the time ... I couldn't taste anything, and I was liquidising everything and I said with [family caregiver] no [to continue medication]. (Frank, P5)

Alternatively, the decision to cease treatment could be made by the patient alone when they had attempted to endure the effects of their treatment but could no longer cope with them. This decision was made when quality of life was perceived by the patient to have been overly sacrificed by them for the purpose of extending their life:

I was just lying in bed. I was just lying there like a ragdoll. That was basically it, I just got fed up with it I just said 'I'm taking no more chemo'... was my decision. I was having that much problems and pains that it wasn't worth it. It was pain every day. Tablets for every single thing. Give him Diafene [pain medication], give him this, give him that. There was only tablets and the bed, that's all. Just lying there and taking tablets. (Anthony, P13)

6.6 Patients trusting family caregiver advice

Patients' willingness to seek support from their family caregiver in decision-making pertaining to their care depended on the degree to which the patient felt trusting of their family caregiver's advice. Patient trust in family caregiver advice was reliant on pre-existing closeness between the patient and family caregiver and the degree to

which the patient perceived the family caregiver was actively involved in and educating themselves about the patient's care:

She finds out initially, I suppose, where the pain is ... Is it a normal pain or is it new pain? She's well up with my medication and she knows exactly what dosage and what drugs. (Mick, P3)

Patients' trust in family caregivers appeared to be enhanced by the co-habitation of the patient and family caregiver. Patients in these instances felt that the family caregiver had a more holistic view of their condition than other family members who were not living with the patient. In these cases, patients were more likely to allow the family caregiver to be an advocate for and/or indeed act as a proxy in decision-making processes if the patient could not come to a decision themselves. In these situations, family caregivers suggested that their ill family member requested their attendance at healthcare meetings because they relied on them for having more expertise on matters relating to the patient's health than the patient themselves:

It'd be just like, if he's going to hospital appointments or anything, he'll always say to me, 'Are you taking me to it?' because 'you know everything regarding the medication and what's happening to me', whereas he feels, obviously, because the others aren't living here, that they don't know enough to tell the doctors. (Jen, FCG16)

Regardless of patients' circumstances, their trust in their family caregiver's expertise was one of the key factors that altered their own approach to decision-making about their care. With exception of 'snap' decisions when the patient was in acute discomfort, patients leaned on their family caregiver for information and advice to assist them to consider their care options as best as possible:

I'm the crisis manager, I suppose. And I'm doing the food and stuff like that, participating in medical interviews, and then my Dad is the main person that she [patient] kind of talks to and confides but I am the person she relies on for ... for kind of factual information. (Craig, FCG21)

Generally, the more the family caregiver attended healthcare meetings and researched treatments and medications for the patient, the more trust the patient placed in the family caregiver's guidance:

She's in there [healthcare meetings] with me all the time because she will ask questions I might never even think about. (Anthony, P13)

Overall, family caregivers were generally respectful of patients' decisions pertaining to end-of-life care because family caregivers were attuned to the fact that they themselves had not experienced the pain and discomfort the patient endured and/or continued to endure. Nonetheless, family caregivers still attempted to advise and guide their respective other in their decision-making to the best of their ability because they wished for them to make decisions about care that would achieve the outcome desired for themselves. Rather than attempting to alter patient decisions, family caregivers for the most part, reported helping patients make decisions in line with the patient's wishes rather than prioritising their own needs with regards to patient care. This was accomplished by family caregivers gathering information sufficient for the patient to make a decision without attempting to bias the patient's choice:

You start to kind of make all the decisions as well whether you're supposed to or not, and my daughter in fairness to her said, like, 'We have to make sure that no matter what's happening with [patient], he is the one who is most involved.' And that we make sure that he understands and that he gets a chance to say what he wants. (Tina, FCG8)

Family caregivers feeling that they were trusted by the patient made them feel part of decision-making in relation to the patient's care. Being a trusted source for the patient also afforded some element of control to the family caregiver by the patient even if the patient's final decision did not concur with their family caregiver's advice:

I would trust [caregiver] to make the best decision for me ... I trust him deeply, that you [speaking to caregiver] know, if you're saying that this is going to do me good. I trust you completely on that. (Irene, P1)

Family caregiver involvement in the decision-making process had benefits for both the patient and family caregiver because it resulted not only in the patient having access to more information through the family caregiver, but also allowed the patient to instill their trust in their family caregiver:

He [family caregiver] was heavily involved [in decision-making], 100%, and always came on the wards on oncology, asked questions, and we'd sit down together ... He's huge, huge influence and never really complains ... it was never a problem for him, never. (Michelle, P11)

6.7 Family caregivers informing themselves about the patient's healthcare needs

Patients' motivation to seek support from their family caregivers in making decisions about their care was influenced in some cases by family caregiver health literacy with regards to the patient's illness and treatment plan. Family caregivers acting in this informed role for patients to alleviate much of the pressure patients experienced in making what patient perceived to be the 'right choice' for their care. When family caregivers educated themselves, the patient reported confidence in the family caregiver and the patient involved the family caregiver more in decision-making processes pertaining to patient treatment and care. In some cases, family caregivers' informed views bolstered patients' confidence in the family caregiver's advice to them:

Teresa [family caregiver] reads through every single leaflet of every single tablet that comes in here. And none of them basically are new at the minute anyway, the only difference might be the dosage might be up or down. That's why we have the conversation there on the phone from the chemist, and Teresa would be aware. (Mick, P3)

6.8 Collective approach to decision-making prompted by change in the patient's cognitive and emotional status

Family caregivers attempted to guide the patient as best as possible in healthcare meetings and in line with how the patient had previously intended for their treatment plans to unfold. In these instances, family caregivers were motivated by the previous decisions of the patient and by how the patient would have responded before their

medication and/or illness negatively impacted on their ability to attend to detail during healthcare meetings. Family caregivers were motivated to be more present in discussions about patient care to ensure that patients could report symptoms or care issues more accurately to healthcare professionals:

I will update the medical professionals [in meeting] about 'No, that didn't happen that way, it happened a different way' or 'No, she's not on this [medication], she's on this [medication] instead.' (Craig, FCG21)

Importantly, family caregivers were able to rely on the advance care plans that the patients had set out including for example, patients expressing that they wished to pass away at home. Here, family caregivers attempted to approach decision-making in a manner that was consistent with what they perceived to be in line with the patient's preference for care that they felt the patient would have communicated in the absence of cognitive deterioration:

She'd turn round and say, 'Is that right' She knows herself the head isn't right. Anybody talking to her she'd refer it to me kind of 'Is that right?' Because she doesn't know herself with the head [cognitive deterioration]. (Seamus, FCG17)

Family caregivers took their lead from healthcare professionals such as palliative care nurses and consultants in palliative medicine, placing trust in healthcare staff to give them the correct guidance for the patient's care. Family caregivers who communicated observing deterioration in the patient's cognitive functioning reported that they would ask healthcare professionals for increased support in the decision-making process for patient care:

I can communicate to him, and then it's his final word and his final say, because my Dad is still there. But with somebody that's not still up there [lucid]? Well then go with professionals. We know they are not there to make life difficult for people. (Frances, FCG9)

Nonetheless, patients remained strongly motivated to overcome any transient cognitive difficulty, such as cognitive deficits resulting from delirium, nausea, fatigue, and drowsiness, which could impact on their ability to retain elements of their pre-

morbid lives, particularly with respect to activities that they enjoyed prior to their illness. Patients' decisions about treatments including medication were carefully considered in the context of avoiding where possible change in their mood and subsequent interaction with their family caregiver:

I know some of the doctors are trying to get me to go back on it. But I'm not going back on something that I know makes me completely uncomfortable, and if I'm uncomfortable, I start to get a bit snappy, and that's not who I am. I love to laugh and joke with everyone. So, that's why I said that when I'm coming off it, I can be happy, I don't want to be turning around and snapping at stupid things that normally wouldn't bother me. (Tom, P14)

For example, in some cases, opioid-based medications caused confusion and delirium for patients. Subsequently, patients considered such medications to be of limited benefit because they restricted their ability to communicate effectively with their family caregiver:

That was frightening when they put me on the extra 10ml tablet. I was getting illusions like looking at little green men hiding behind trees looking at me... I remember bits and pieces but not everything. That was frightening not [to be able] to communicate [with family caregiver]. (Stephen, P15)

Patient irritability and change in their mood could impact adversely on the patient and family caregiver relationship particularly during end-of-life care for the patient. In some cases, the patience and resilience required from family caregivers during this period of care caused strain for both patients and family caregivers and was catalyst for family caregiver burnout:

He's [patient] got very finicky since he got the cancer. Normally, he's always in great form, he's happy go lucky guy... I get a lot of that off him, sometimes I would have to bite my lip, walk out to the hall, take few deep breaths, and walk back in, you can imagine. But it's not, it's not him, it's the pain. (Teresa, FCG3)

Patients struggled to reciprocate support to family caregivers when in distress. This could in turn lead to feelings of hurt and resentment in family caregivers and feelings

of guilt and burden in patients. In these situations, the patient and family caregiver had to discuss the potential impacts of treatments on patients' mood and coherence when making decisions about specific treatments:

We sort of decided, early on with the steroids, they make you high and low and you can get very cranky. And I explained that to her [family caregiver] that if I do get cranky, I don't mean it. It's those steroids and the Oramorph, morphine or whatever, so you have to understand that. (James, P8)

In a small number of cases where change in patient personality had extended to confusion and cognitive difficulty, family caregivers struggled with having to act on the patient's behalf. If patients were experiencing a period of cognitive decline due to their illness or medication, family caregivers felt uncomfortable due to the patient's potential lack of consent when receiving treatments or making other care decisions and acted as proxy for them in decision-making situations. In these situations, family caregiver reported that they acted in good faith, making the decision which they strongly felt that the patient would make for themselves in the absence of cognitive impairment:

My mam can be quite confused so sometimes I don't know if she even knows what's going on. Like she was saying to me the other day, 'Sarah, I hope the cancer won't come back' ... [So] I would probably make more of the decisions, not give her so much of a choice. Now if it's something small where I can give her a choice, I'd love to give her choice, but I'd be trying to say to her 'Mam, I'm making the right decision for you, because this is safer for you.' Her medication, she wouldn't know, sometimes she'd say 'What... what am I taking?' when I am giving her tablets, and I would say 'Mam it's just a very slow release painkiller, you know, you're a bit shaky, that's why I'm giving you this.' So, she sort of just says okay, so she'll go along sort of with what I tell her. (Sarah, FCG4)

While it was generally the wish of the family caregiver to lengthen the patient's life when voicing their preferences for the patient's treatment, there were exceptions to this norm. Family caregivers were strongly motivated in their decisions by retaining the patient's personality as much as possible even with risk to the reduction of the

patient's life. Family caregivers expressed that they would rather have the patient for less time if they could remain 'themselves' instead of the patient living longer and experiencing change in their personality. This was particularly the case with respect to the experiences of patients and family caregivers who were spouses and who had dependent children whereby both patient and family caregiver prioritised their children's needs over their own needs. Here, both patients and family caregivers supported each other by mutual effort not to appear distressed to their shared dependants:

What my treatment from the family's [family caregiver and dependants] perspective is, they seem happier if I can be the me that they know as much as I possibly can be, through taking either rest or taking some counselling... or taking a mixture of counselling and anxiety medication ... I think the family are sort of happier with that. They know that I am still trying my best and I'm still trying to be the person that they would recognise. (Frank, P5)

6.9 Family caregivers upskilling themselves to assist in the decision-making process for care

In preparation of supporting patients in the decision-making process for care, some family caregivers felt a responsibility to gather as much information as possible about the patient's illness, aware that patients might struggle to gather information themselves. Family caregivers facilitated patient decision-making by researching information regarding the patient's prognosis, potential care options, and the range of medications offered to the patient as they advanced in their illness. Moreover, family caregivers faced the additional challenge of safeguarding patients from COVID-19 and placed pressure on themselves to become experts on the patient's care in the context of COVID-19. In many cases, the high expectations family caregivers placed upon themselves in their caregiving roles served to heighten their own levels of distress. As a result, family caregivers impressed upon themselves the necessity to acquire knowledge and skills to navigate situations faced in their caregiving role which included knowing how to cope with emergency situations:

He [patient] was in pain that we couldn't control and we didn't know how to control it. So, like the whole anxiety of all of that and being helpless, and not

knowing just like the hours, each hour felt like multiplied by ten, and the stress levels were huge on everybody's part. That's always in the back of my mind generally. (Laura, FCG2)

Being responsible for the patient's medication adherence, personal care, and scheduling of appointments with healthcare professionals was taxing and for some family caregivers, an overwhelming experience:

I wasn't expecting to be so overwhelmed by 'What time did she get those tablets at?' and 'Did you change her patch?' or 'What time did you change her [medication] patch at?' Like you're passing the information on to someone else, and you forget and the panic when you think you haven't done something right ... I don't know what I was expecting but I wasn't expecting it to be so mentally draining. (Niamh, FCG20)

Nonetheless, family caregivers who accompanied patients to healthcare meetings were able to assist in the decision-making process for patient care because they had a close relationship with the patient's palliative care team. By maintaining proximity to the patient's palliative care team, family caregivers ensured that they were fully briefed on the patient's care needs. Family caregivers' proximity to healthcare professionals overseeing the care of the patient also ensured that they were suitably prepared to provide care at the end of life that was consistent with the patient's intended care:

I really want to learn how to deal with the situation, know what [family caregiver] wants... because we've never had to deal with this [patient's needs] before. (Kelly, FCG6)

6.10 Patients concealing their wishes from family caregivers

Patients often strove to conceal their true wishes for their own end of life in favour of their family caregiver's wishes, particularly at the outset of engaging with palliative care services. Family caregivers reported having approached the early phases of palliative care with unrealistic optimism, while patients typically held a more realistic view of their circumstances from the outset. Whereas family caregivers were often disapproving of patients' voluntary cessation of curative treatments such as

chemotherapy and radiation, many patients felt that they did not want the quality of their remaining life to suffer for the perceived minimal difference curative treatments would make to the quantity of their remaining life. In these situations, patients often felt they could not discuss the reality of their decision with their family caregiver particularly in the early phases of treatment. Regardless of the decision patients came to with their family caregiver about life-prolonging treatment, patients feared that having a frank discussion based on the reality of their prognosis would cause the family caregiver significant distress:

If I sometimes need to talk to somebody without the family, I don't think that I'm being negative or thinking the worst or that people are going to think I'm thinking the worst, but I do need to be able to talk about reality of what way things are going. I get a bit down. So, it's dealing with that, that side of the family, it's a bit hard because we feel like I'm going on without them but it's not ... I don't think there's really any point in making things worse for them than there is if you like, if I can just deal with that myself. (Frank, P5)

In most cases, patients were particularly advanced in their illness had become fatigued and were no longer able to conceal their symptoms. Patients at more advanced stages of their illness reported that they were unable to endure any more life-prolonging treatments or care that their family caregiver and other family members had expressed preferences for:

I know the two of them [my daughters] ... even from yesterday are completely supportive about this which I really appreciate. And I know it's killing them thinking 'Oh god what if it goes quicker' but as I said we have to wait and see as I said the scan. But the support will be there because I'm opening up a bit more because I'm so ill. (Louise, P6)

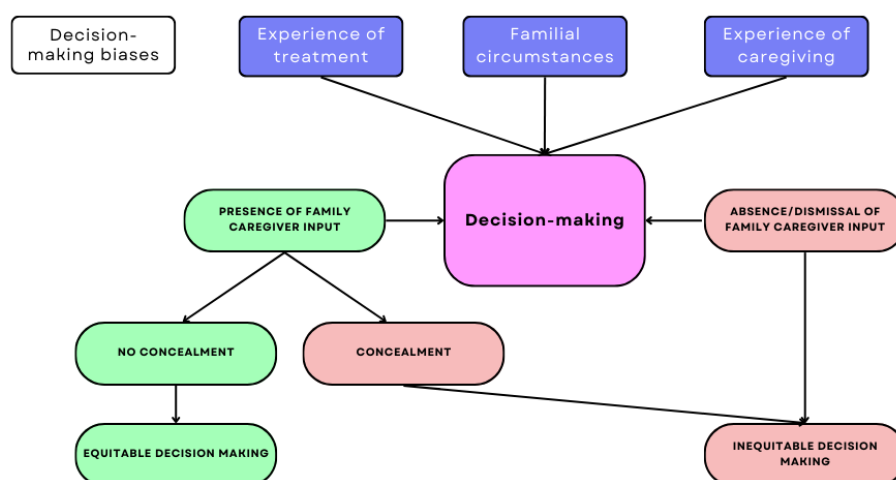
Patients then tended to move from their own family focused care plan to a more patient focused plan with their family caregiver encouragement. Once family caregivers observed the patient's degree of pain and discomfort, family caregivers sacrificed their own wishes to entirely centre care decisions solely around the patient. Family caregivers were reluctant to cause any undue distress for the patient and

actively discouraged the patient to continue with treatments if they caused distress for the patient and/or did not have tangible benefits for the patient:

When it came to her chemo ... she was the only one who could decide if she wanted to keep going even though it wasn't helping her and it wasn't going to help her, it was going to make her sick. So, I suppose we convinced her there was no point, even though for a couple of months she kept saying 'No, I'm going to take it, I'm going to pay for it' and we said 'Okay, it's your body if you want to do it' and then when she talks to the hospice she just decided no, she wouldn't do it. (Sarah, FCG4)

For some, concealment felt dishonest, with some concealers perceiving that their masking of symptoms was disallowing their counterparts to fully understand the reality of their shared situation. The concealment of certain symptoms or distress was indeed inhibitive for patients and family caregivers attempting to make measured decisions, as they were experiencing inequity in terms of the information they had access to. Concealment, while often beneficial in the day-to-day lives of patients and family caregivers, was broadly inhibitive in decision-making despite its good intentions. Decision-making and the role of concealment within it is illustrated in figure 8 below.

Figure 8. *Factors influential on equitable decision-making*



6.11 Life stage and family roles: Context to patient and family caregiver shared decision-making

Decision-making between patients and family caregivers for patient care was shaped by the life stage of patients and family caregivers and the roles that the patient and family caregiver held in their family, as illustrated in figure 8 (pg. 172). In contexts where self-reported 'stubborn' fathers who were patients became care recipients of their adult-daughters, daughters most often relinquished control to their fathers and supported their father's wishes. However, relationships between mothers who were the patient and their adult-daughter their family caregiver were less likely to be this unequal, with daughters reporting that the closeness of their friendship and openness of disclosure enhanced their ability to make decisions with the person they cared for.

Patients and family caregivers who were spouses tended to be more collective in the decision-making process for patient care. This was explained by spousal patients and family caregivers making decisions with attention to how such decisions might affect their children, whether adult children or dependants, that they were rearing or had reared. The reduction in prioritisation of their own individual interests in favour of the interests of their dependants seemed to make decision-making processes more straightforward for spousal patients and family caregivers that were parents of shared dependants. However, decisions were made more difficult for patients where their adult child was acting as their family caregiver. Here, the parent patient wished to act in the interest of their filial family caregiver, but their filial family caregiver wished for the outcome that would reduce the patients' suffering. The following sections of 6.11.1 to 6.11.3.2 outline and explain key dimensions to patient and family caregiver decision-making in the context of both life stage and family roles.

6.11.1 Life stage of spousal patients and family caregivers

The decision to select a treatment plan focused on either quality or quantity of remaining life was shaped by the life-stage of participants. Patients and family caregivers who were spouses made decisions along a trajectory dependent on their similar life stage. Spousal patients and family caregivers who were young or middle-aged tended to prioritise extending the patient's life, whereas older patients (over 70 years) and those who were their spouses tended to prioritise the quality of the

patient's life over extension of the patient's life. Patients and their spouses who were middle-aged or younger felt that they had not lived a full life together and were determined to realise as many of life's milestones as possible which included for some, their adult or dependent children's own milestones. Middle-aged patients and those younger together with their spousal family caregivers felt that they may respond better to aggressive treatments and were more likely to choose these treatments than older patients. Whereas older patients (over 70 years) felt their lives had been naturally slowing regardless of their illness, young and middle-aged patients and their spousal family caregivers often felt angry about the limited options available to them:

People say you should be angry you're only 60. You know, you should be angry, and you should be this you should be that... it's unfair and I have a sort of anger now. (Frank, P5)

Patients and family caregivers supported one another in offering understanding to their counterpart of a differing life stage i.e. parent and child, and creating a shared reality with counterparts of the same life stage i.e. spouses. This manifested in children family caregivers being sympathetic to their parent patient wishes to cease curative treatment for example, or in the case of spouse caregivers supporting the patient in opting for aggressive treatment to lengthen life for shared dependents as will be discussed below (section 6.11.2).

6.11.2 Making decisions about care in the context of shared dependants

Patients and family caregivers with dependants were a subgroup that made decisions differently to all other types of patients and family caregivers. Decisions of patients and family caregivers who were parents of dependants were made with a heavy focus on the welfare of their dependants. Dependents, for the purpose of the present study, are defined as any child of a patient (including adult children) who relied upon the patient for housing or financial support. Here, patients chose more life-prolonging treatments to prolong their lives rather than attempt to reduce pain and discomfort. This self-sacrificial decision while typically discouraged by family caregivers outside of this context, was encouraged in this situation, with both patient and family caregiver attending to their shared children's needs before either of their own needs. Patients who were parents of dependent children expressed a strong desire to retain their

parental roles for as long as possible and for the sake of their children for whom they still provided an essential role to:

I'm there as a sounding board for my daughter, that will never change. So, in that role, I'm still her mother. And you know that ... for as long as I draw my last breath, I'll be her mother ... I want to be around for as long as I can for them both [spousal family caregiver and daughter]. (Irene, P1)

Patients who were parents of children who still depended on them saw the prolonging of their lives as their highest priority in terms of their desired care outcomes despite the negative effects of aggressive treatments to prolong life. The prioritisation to prolong their lives where possible was particularly true of single-parent families, where the parent patient was the only guardian that remained for their dependants:

I know what I want, exactly what I want. Wouldn't change my mind if it was the girls [teenage daughters] or some other carer or whatever. I think I know exactly what I want when it comes to the time... If I had to ... if I had a choice to offer the more aggressive treatment and spend more time with them, absolutely or take more aggressive treatment. Absolutely. (Neil, P7)

Patients with children who were still dependent on them were motivated not only to prolong their lives for as long as possible for their dependants, but also to prepare meticulously for their own deaths, both practically and financially. Patients felt that keeping their children fully informed with regards to the reality of their circumstances and allowing their children to have input in decision-making in their end-of-life care would also help prepare them for the impending loss of a parent. Indeed, patients felt that involving their children in these arrangements were needed to force more avoidant dependants to accept the reality of their collective situation:

It is killing me to see them. And my son is a different case, he's kind of ignoring everything. But I worry for him because he's only 21. I find he wants to just ... to just he doesn't want to know anything. He doesn't even want to account for it, and he's just like nearly ignoring me sometimes. (Louise, P6)

Regardless of how dependent or not patients viewed their children to be, patients and their family caregivers involved the children they shared in planning for patient care including the patient's preferred place of death:

[Family caregiver and I discussed] just the whole process of me passing on, and what my wishes are and this, that and the other, and we got it sorted ... that was a big, big, big, big sort of what ... what would we call it? A big emotional thing you know. (Neil, P7)

6.11.3 Change in caregiving roles for patients and family caregivers

While patients and family caregivers claimed to be living 'day-by-day' to cope with instability and unpredictability of their lives, a number of historical factors also permeated their decision-making processes and their framing of their shared circumstances. Both patients' and family caregivers' previous experience of illness and caregiving, whether their own or observed in others, influenced their approach to decision-making in relation to palliative care. In addition, patients' and family caregivers' experiences in their previous familial roles and the ways in which they had previously given or received care within these roles affected the ways in which they behaved in their new roles. Sections 6.11.3.1 and 6.11.3.2 explain key dimensions to change in caregiving roles for patients and family caregivers in the context of decision-making.

6.11.3.1 Family caregiver 'turn' to provide support to their ill parent

Motivations for both patient and family caregiver decisions were influenced by the parent patients' previously held caregiving roles within their family unit. This occurred primarily in relationships between parents who were patients and their family caregiver non-dependent adult child, and where caregiver and care recipient roles had to be exchanged between the parent and their adult-child family caregiver:

Obviously I want to do everything I can for her [patient] and everything she wants, but she's just looking out for her so it can be quite hard. But look, I'm just doing the best I can do ... I feel I can't do enough for her ... she's having a nice experience and a nice end of life and I am sort of glad as well of the opportunity [to repay her]. (Sarah, FCG4)

Family caregivers were motivated by feelings of anticipatory grief and the knowledge that their remaining time with their parent that they cared for was limited, attempting to repay care that was provided to them by the patient earlier in their lives. Family caregivers' perception of the quality of care they themselves had received from the patient prior to the patients' illness impacted on the efforts family caregivers made to ensure the patient wishes for end-of-life care were catered for. Many family caregivers in this position reported a wish to have a 'clear conscience' following the death of the patient. Wanting to have a 'clear conscience' following the death of their loved one underpinned some family caregivers' exhaustive efforts in this regard:

That's what kind of gets me through the day and knowing that if he [patient] calls out, I'm here and it's me that is looking... will do whatever he wants. That's kind of what gets me through. I always said that when he dies, my conscience will always be clear because I've done the best for him. That's what gets me through it. (Frances, FCG9)

In addition, family caregivers were motivated to give care to the same standard as they received it from the patient in the past. This type of family caregiver was far more likely to be motivated by the wishes of the patient rather than enforcing what the family caregivers perceived to be the patient's needs. These family caregivers reported that they attended to the patient's wishes to repay the debt of care they had already received from them:

I would love to... to help my mam like you know... because she's done so much for us as a single parent, like she was always there... so I think that would be nice to return the favour ... We [family caregiver and sibling] would love to like bring her out more places and stuff like that ... just to be there for her and help her and do as much as I can. (Kelly, FCG6)

For a small number of family caregiver participants, caring for their family member patient was motivated by the notion that they too would need family caregiving at the end of their own lives. This motivation to paying their caregiving efforts forward was prevalent in the data of those who had experienced a significant amount of death due to life-limiting illnesses caused in many cases by cancer:

All the females in my family are dead. I'm the last, and they all died under the age of 50. So, I made it to 50! [laughs] It was an ongoing bet with us, with the kids, the young kids and husband, 'Will you hit the 50 mark?' ... I got to 50.
(Frances, FCG9)

6.11.3.2 The effects of previously held family roles on newly adopted patient and family caregiver roles

Family caregivers who were the adult children of the patient adjusted to their new roles with varying success, all reporting varying degrees of the continuation of some elements their previously held familial roles. For some, the reversal of the caregiving role was an advantage to intuitive care, making attending to the patient's wishes almost automatic when they understood the types of support the patient valued from them before their illness:

I suppose, knowing it's my dad, like there's no worries or anything there, he knows that he can rely on me constantly. I kind of feel as well that while we were growing up, they gave us the care that we needed. So now it's just kind of like reversing the roles. And it's still a natural thing to me, just to care for him ... it's just a natural thing. (Jen, FCG16)

However, the retention of elements of previously held family roles also acted in some cases, as an obstacle in the decision-making process for care with patients who were parents more likely to minimise their adult-child family caregiver's opinion, particularly in the case of patients who were fathers of their family caregivers. These patients, in line with their attempts at stoicism, were less likely to take a collaborative approach to decision-making, instead insisting that care plans were alone their choice:

I don't rely on her [family caregiver], I don't rely on anyone. I'm a very stubborn person ... I said that to them [my family], and that's what I would base my decisions on, what I'm going through, not what other people tell me. (Tom, P14)

Occasionally, family caregivers expected less of the patient as a support because of their own reluctance to burden the patient. In some cases, family caregivers found the

role change of parent to patient and adult child to family caregiver difficult as they felt they lost their parental figure in the process and were afraid to burden the patient with their own problems as they had previously done. Observing their parents transitioning from strong parental figures that family caregivers had previously considered them to be, to medically vulnerable patients unable to provide the same sense of safety and protection they once did, was emotionally distressing for the family caregiver:

I get upset... when you can't tell her... when you can't tell her things anymore.

(Niamh, FCG20)

Overall, these family caregivers wanted to honour the wishes of their parent and perceived that it was not their place as the patient's child, even in the cases of adult-children, to influence the patient's decisions about their own care:

So they [healthcare professionals] are telling me [information regarding his illness and treatment plan] and I can communicate to that to him, but then it's his final word and his final say. (Frances, FCG9)

6.12 Previous experience of life-limiting illness

A proportion of patients and family caregivers in the study already had experience of palliative care when another family member had accessed palliative care in the past. These experiences shaped both patient and family caregiver preferences for care in terms of how they now sought to be mutually supportive in a caregiving relationship, as illustrated in figure 8 (pg. 172). Sections 6.12.1 and 6.12.2 explain how previous experience of life-limiting shaped patient and family caregiver approach to decision-making in the context of mutual support.

6.12.1 The influence of prior caregiving on patients' and family caregivers' preferences for care

Patient and family caregiver care preferences were shaped by their experiences of having cared for another family member. Some patients were witness to the deaths of family members who had attempted to prolong their lives with radiation therapy and/or chemotherapy. If the end-of-life of their family member had been particularly difficult, these patients were conscious not to overly burden their family caregiver:

I watched my brother die, he was only 39 and I went over to see my sister in Australia before she died, she had cancer as well... I know I'm going to die. So why burden? (Tom, P14)

Patients who had watched and cared for family members and who had used palliative care services had different views from patients who did not have experiences of such. These patients often utilised negative experiences of their family member's deaths to decide themselves what treatments they wished to have or not to have after having already witnessing a family member endure its effects. In this context, these patients did not want to further exacerbate their family caregiver's distress and strain in a caregiving role:

Now I found that's when I really want to go into the hospice, because I wouldn't like them to look after me like that way because I used to look after my own mother when she'd cancer and I wouldn't put them through it. That was extremely, extremely hard for me now. (Louise, P6)

Family caregiver prior experience as a caregiver of other family members influenced the way in which they inputted into decision-making pertaining to the patient's care. Family caregivers who had prior experience of family caregiving reported having well developed coping skills which assisted them in their role as family caregivers for the patient receiving palliative care. These family caregivers were motivated by their previous experiences and informed by any errors they felt they made in prior caregiving roles. However, their prior experience of caregiving also served to remind them of the distress they encountered when caregiving. Nonetheless, family caregivers who had already cared for an ill family member had typically self-selected themselves as the primary family caregiver when compared to those who did not have prior experience of caring for an ill family member:

My first experience [of undertaking family caregiving] with my father ... when he [father, ten years ago] was diagnosed [with cancer], I literally packed up my house and moved over to his house to give him 24-hour care. So, it's not my first experience [as family caregiver by choice]. (Teresa, FCG3)

6.12.2 Patient and family caregiver experience of services prior to hospice care

Patients' and family caregivers' view of how healthcare had been delivered to the patient over the course of their illness influenced how both engaged in the decision-making process for care. The ways in which patients were treated in formal healthcare settings influenced both their and their family caregiver's opinions on their ability to trust and rely upon healthcare professionals. Whilst patients and family caregivers were generally satisfied with and trusted their hospice care teams, their shared experience of treatment while the patient was in a hospital setting was markedly different. Most patients and family caregivers felt that they could not trust hospital staff to give care to the standard of the family caregiver which caused high levels of distress to both patient and family caregiver. In some cases, patients' and family caregivers' avoidance of hospital-based care was explained by the how it could possibly limit their communication and time together:

Because of COVID she [patient] won't [go to hospital]. That's her objection. There's no visitors. And as I say she was in a while ago and would ring the hospital... [but] they weren't answering the phones, so we had no information whatsoever. She actually fell in the hospital, and they never notified us.
(Seamus, FCG17)

Patients' negative experiences of care in hospital settings meant that they were reluctant to seek emergency assistance from hospitals. However, family caregivers reported that they had to on occasions override the patient's wishes and that this could result in conflict between them and the patient. Family caregivers reported that they needed to assure the patient that they would advocate for the patient to return home as soon as possible:

I said to [patient] 'I think you are going to have to go get that thing stitched' ... my Dad said 'Well I don't really want to go.' So, I just said, 'look we'll go get it stitched, and I won't let them keep you. Because or else' I said, 'it will be only overnight' I said 'and you will be back in the morning', I said, 'so they'll let me stay with you.' (Frances, FCG9)

Incidents of the above nature tested the patient and family caregiver relationship because they were the few occasions that the family caregiver felt they could not honour the patient's wishes and sought to encourage the patient to take a different course of action contrary to what they wished. These incidences were a significant motivator for family caregivers to seek palliative care for the patient from community-based hospice care. Family caregivers, despite their own doubts and concerns about the patient's care whilst in hospital, often had to call for assistance due to their own lack of medical expertise and uncertainty in the face of symptom severity. When combined with the resistance of patients to attend hospital-based care, some family caregivers became highly motivated to self-educate and seek information from hospice-based services so that they could effectively provide care to the patient in the home. This was appreciated by patients who knew that their preferred location of care was reliant on their family caregiver's efforts:

I loved the fact that I didn't have to go to a hospital, have to leave the house ... I completely rely on him [family caregiver] just 100%. I completely rely on him for everything and he's just been an absolute rock to me. (Irene, P1)

6.13 Chapter conclusion

This chapter has shown that patients' and family caregivers' decision-making in palliative care was a multi-faceted and complex process shaped by both interpersonal relations and the experience of palliative care. Although a minority of patient participants preferred to have substantial control over their decisions about treatment and care, most patients preferred to make decisions with their family caregiver or at least involve family caregivers directly in discussions about their treatment and care. Patients and family caregivers who were spouses participated in shared decision-making more equitably than other type of family caregivers. Overall, family caregivers were strongly motivated to make decisions with the patient and to honour the patients' wishes. Their motivation to do was explained in some cases by the nature of their relationship with the patient prior to the patient illness and by their previous experience of family caregiving. Family caregivers in the study were conscious to support the patient's choices.

Patients' decision-making for treatment and care was shaped by factors such as their severity of symptoms, their perception of the wishes of their family caregiver and wider family, and by their previous observation of a family member experiencing a life-limiting illness. Patients appeared to make decisions dependent on their life stage and family circumstances, with younger patients who had dependants highly motivated to continue to live and to be active in their supportive roles. Overall, making decisions together was a form of mutual support between patients and family caregivers. The next chapter (chapter seven) discusses the key findings of the study.

Chapter 7: Discussion

Chapter 7: Discussion

7.1 Introduction

This chapter discusses the key findings presented in chapters four, five, and six. It is important to note that the experiences of participants in the study were captured at different points of palliative care utilisation for participants. While some patients died and some family caregivers were bereaved very shortly following their interviews, some patient participants continued to survive for a period after their participation. Overall, the study captured participants' experience along different points of services utilisation, at different life stages for participants, in different familial-based relationships, and in the context of both similar and different perspectives pertaining to palliative care.

The present chapter will discuss the findings of the previous three chapters in the context of pre-existing literature pertaining to patients and family caregivers in palliative care, dyadic models of care, and decision-making at the end of life. The present chapter will also discuss the findings of the present study as they relate to the findings of the studies discussed included in the systematic review (chapter 2).

7.2 Discussion of key findings

7.2.1 Patient and family caregiver relational experience in palliative care

In the present study, family caregivers struggled with the range of responsibilities they were newly undertaking in addition to their adjustment to the reality of the patient's diagnosis and subsequent illness and to change in their own lives as a result of the patient's illness. Family caregivers experienced strain with even the most seemingly natural or indeed professionally trained family caregivers experiencing elements of psychological distress. The challenges experienced by family caregivers of patients with palliative care needs are often so copious and severe that a cluster of psychological co-morbidities occur, with symptoms such as depression, anxiety, complex grief, acute distress, and posttraumatic stress (Davidson et al., 2012). It is known that family caregivers experience cognitive dissonance in holding roles in both the unit of care and

the care team (Sherman, 2019; Smith, 2014). While formal supports were in place for family caregivers in the present study (e.g., support from healthcare professionals), family caregivers reported that they undertook more caregiving than they had done previously and presented with emotional and physical distress as did the terminally ill family member which they provided care to. The adjustment to this new, more responsible role for family members and the relinquishing of caregiving responsibilities of patients found in the present study was mirrored by the findings of the systematic review (chapter 2) which informed the present study (Ando et al., 2019).

Existing research on family caregivers in palliative care has primarily focused on the family caregiver experience as it relates to the patient, with the aim of optimising the ability of family caregivers to give optimal care at the forefront of services (O'Hara et al., 2010). As already outlined, family caregivers are considered a part of the unit of care, due in part to the reliance of health services upon them to ensure continuity of care (Veloso & Tripodoro, 2016). Patients, as found in the present study, did not generally experience anxiety due to the fear that their family caregiver would give sub-optimal care as a result of family caregiver distress, but rather their distress arose out of concern for the wellbeing of their family member, as identified in the systematic review (Ando et al., 2019; Badr & Taylor, 2006; von Heymann-Horan et al., 2019) carried out as part of the present study (chapter 2). Participants in the present study reported repercussions to their choices and/or decisions made in palliative care not only for themselves but also in relation to one another. These findings are consistent with existing research on the experience of palliative care as reported by patients and their family caregivers (Combrink & Maree, 2016; Norinder et al., 2017; Veloso & Tripodoro, 2016; Wilson et al., 2013).

7.2.2 Motivations to give and receive support

The study has identified that patients and family caregivers are motivated to both give and receive support, and accept or reject support, based on a range of factors. Family caregivers' motivations to provide support to the patient were influenced by their own perceptions of their circumstances, which in turn shaped the care received by the patient and affected the patient's perception of their own circumstances. Some family

caregivers were clearly motivated either by personal responsibility, taking on caregiving duties voluntarily and with enthusiasm, or by obligation, taking on caregiving duties out of need, with a lack of other suitable candidates available in the wider family to assume a caregiving role. Those who clearly adopted the role of family caregiver out of obligation usually did so as no other family members were suitable or available and which further compounded family caregivers' feelings of obligation. Such situations resulted in these caregivers having a lack of external support to assist them with their duties. Conversely, those who adopted their roles with a sense of enthusiasm were often supported in their roles by other family members, as these caregivers typically reported they were a part of cohesive and harmonious family units, where other family members were willing to assist in caregiving duties, further alleviating the primary family caregiver's burden.

The above two groups of family caregivers, those who took on caregiving duties voluntarily and those who felt highly obliged to care, differed from one another in role satisfaction. Family caregivers who felt they assumed caregiving by their own choice expressed more satisfaction in their role than those who felt they had little choice but to assume a caregiving role. However, not all family caregivers fell easily into the above categorisation. More often, the confluence of two motivations, namely personal responsibility and obligation were observed in a number of family caregivers. Family caregivers were therefore deemed not exclusively obligated or personally responsible, but more obligated than average or more personally responsible than average, depending on the degree to which they self-disclosed these motivating factors within their interviews. These findings were not identified in the systematic review carried out to inform the present study, suggesting that the delineation between personally responsible and obliged caregivers was a novel finding.

The majority of family caregiver participants were motivated more strongly by personal responsibility than obligation, concerned primarily with ensuring that their remaining time before the patient's death was spent harmoniously with the patient, sharing positive experiences and spending remaining limited time together. This is consistent with previous research investigating the primary motivations for family caregiving in palliative care, which identified that the primary motivations for caregiving among

family caregivers was the preservation and amelioration of the personal relationship between patient and family caregiver (Kolmer et al., 2008). However, Kolmer et al. (2008) also report other factors which motivate family caregivers to adopt their caregiving roles which included filial family caregivers' motivation to provide care to repay perceived caregiving debts to their parents, and spousal caregivers wish to ensure that the dependants they shared with the patient did not feel responsible to provide care. The findings of the present study resonate with those of Kolmer et al. (2008).

Patient and family caregiver closeness and open disclosure were dimensions to mutual support that assisted both the patient and family caregiver to support one another. Previously conducted research (Tsilika et al., 2015) supports this finding, with evidence highlighting that a high degree of closeness and security within a patient and family caregiver relationship can increase both patient and family caregiver self-efficacy in managing their counterpart's distress. In addition to secure relationships improving self-efficacy in patients and family caregivers, the present study identified that strong relationships also allowed for patients and family caregivers to better understand one another in terms of what supportive acts each other most appreciate receiving and which they are capable of giving to one another. Closeness and familiarity within the patient and family caregiver relationship have the ability of enhancing intuitive support thereby increasing the impact and efficiency of each supportive action (Haan et al., 2021). Therefore, in understanding one another, patients and family caregivers can reduce attempts at trying to give the optimal type of support because they can intuit what supportive act will be of most benefit to their counterpart. The successful exchange of support between patients and family caregivers in the present study was the basis for reducing mutual strain between the patient and family caregiver. The findings point to the value in treating the patient and family caregivers as unit of care as opposed to treating the psychosocial symptoms of both patient and family caregiver in isolation (J. Li et al., 2023). Despite these intuitive benefits, the systematic review carried out as part of the present study indicated that a strong degree of emotional relatedness can result in shared escalation of negative as well as positive emotions, and that the emotional wellbeing of each individual is reliant on the emotional state of

their counterpart (Ando et al., 2019; Badr & Taylor, 2006; Persson & Sundin, 2008; von Heymann-Horan et al., 2019).

7.2.3 Quality of relationship between patient and family caregiver

As identified in the present study, a key context to patient and family caregiver motivations to provide support to one another was the quality of their relationship. A factor that has been overlooked until recent years is the influential nature of the pre-morbid relationship between the patient and family caregiver in palliative care. A strong relationship between the patient and family caregiver was not solely a driving force for providing support to one another but was also a key factor in sustaining the stamina and resilience to maintain and bolster a supportive relationship in the face of significant adversity. Previous research has highlighted the importance of a close partnership between patients and family caregivers stating that closeness offered patients a sense of security and comfort (Milberg et al., 2014) while these relationships were also protective for family caregivers (Reblin et al., 2016). Reblin et al. (2016) identified that family caregivers can be protected by having a strong relationship with the patient, by managing their burden, by having self-efficacy in their roles, and when they maintain their sense of purpose within their roles even when they experience distress. In the present study, patients and family caregivers who reported strong relationships with the patient they cared for also felt they were part of families that functioned well. The function of the family appeared to affect the relationship between the patient and family caregiver in part because of the of poor family functioning on patient and caregiver burden and as evidenced in previous research (Carolan et al., 2015; Milberg et al., 2020; Yoon et al., 2014). For these reasons, it appeared that family caregivers who were motivated by personal responsibility were more likely to have the autonomy to do so, aware that they would receive support from the wider family. In this way, these family caregivers felt more capable, adaptable, autonomous, and secure in their roles than obliged family caregivers.

As stated, family caregivers who assumed their caregiving roles through personal responsibility did so due to their genuine desire to care for the patient. Concurrent with the findings of Henriksson et al. (2015), patients who self-selected their role

reported that they felt rewarded by the sense of satisfaction that came from providing support appreciated by the patients and the shared happiness, purpose and meaning that resulted from providing such support. The degree to which a family caregiver felt able to experience these rewards and indeed the feelings which motivate them to assume their roles is reliant on the close relatedness they perceive existed between them and the patient. The traditional idea of the purely altruistic and compassionate caregiver with no consideration for their own needs has been contested by modern literature, particularly the work of Pettersen (2012) who states that the optimal caregiving model is 'mature care'. Mature care considers the complexity of motivations to care, particularly the complexities in the relationships between patient and family caregiver, emphasising 'the expression of the relational and reciprocal aspects of caring while emphasizing the equal worth of all involved' (Pettersen, 2012, p.366). Family caregivers in the present study who assumed caregiving duties out of personal responsibility had the flexibility and autonomy to advocate for the needs of the patient. The quality of the relationship between the patient and family caregiver was very much dependent on how patients and family caregivers sought to support one another when their motivation to care was not just underpinned by obligation but more so by a genuine desire to provide support to the patient.

7.2.4 Personal responsibility between patient and family caregiver in decision-making for treatment and care

Family caregivers who did not feel heavily obliged to care approached decision-making for patient treatment and care with a strong sense of personal responsibility to the patient. Patients' decision-making about their treatment and care was also influenced by the degree to which patients felt or indeed the degree to which they cared that their decisions would impact on others and what impacts these decisions would have for the family caregiver. Delegating elements of the decision-making process to family caregivers allowed patients to collect more information about their illness and treatment options through family caregiver and which is supported by other research (Dionne-Odom et al., 2019). Patients' involvement of family caregivers in early decision-making is understood to allow family caregivers to become 'trained' on how

the patient typically comes to a decision including the patient's attitudes concerning quality versus quantity of remaining life and their preferences for end-of-life care (Perkins, 2016). Indeed, a lack of discussion between the patient and family caregiver regarding the end-of-life care of the patient can lead to patient and family caregiver disagreement when deciding about treatment and care (Shin et al., 2015). Involving family caregivers early on in decision-making can also help ensure that decisions made for patients when patients are incapacitated to make decisions about their care are consistent with what the patient would have decided had they been sufficiently capable of deciding about their care (Edwards et al., 2012). In the present study, overall, patient and family caregiver personal responsibility to one another in the decision-making process pertaining to treatment and care was deemed by both patients and family caregivers to be beneficial for one another.

7.2.5 Family caregiver perceived obligation to patient

The concept of obligation has been previously investigated within the context of family caregivers, particularly in family caregivers living in societies where filial piety is a cornerstone of the culture (W. Li & Keerthigha, 2021). The expectation on an individual to fulfil the role of family caregiver may leave little opportunity for these individuals to perceive that they have a choice in their assumption of their caregiving roles. In the present study, the author identified that a sense of autonomy and control in assuming a caregiving role allowed family caregivers to develop in the role of caregiver particularly when they assumed their role by choice and not simply because of obligation. However, feelings of obligation for family caregivers were compounded when family caregivers were obliged to cease other parts of their lives because the lack of support which they received from other family members in their caregiving. This was noticeable where family caregivers were part of the 'sandwich generation', a term given to individuals both providing care to the generation above (parents) and below (children) them (Abramson, 2015). Family caregivers can experience cycles of distress in which they experienced anger and resentment followed by remorse and guilt, with eventual return to irritation and the inability to suppress their emotions (Ong et al., 2022). In the present study, the above inhibited mutual support between patients and

family caregivers because family caregivers indicated that such emotions impeded them to foster the patience and compassion required to both give and receive support.

7.2.5.1 Family caregiver obligation: Impact on decision-making for treatment and care

While family caregivers, as mentioned, fell across a spectrum of how obligated versus personally responsible they felt towards the patient, more obligated family caregivers acted differently in decision-making discussions when compared to family caregivers who felt less obligated in a caregiving role. The present study found that conflict between patients and family caregivers often manifested in disagreement about treatment and care. This conflict resulted in distrust in one another, with patients feeling that family caregivers were attempting to gain control of the patient's decisions about their care and with family caregivers insinuating that patients over-exaggerated or underplayed their symptom severity to healthcare professionals. These findings resonate with Mulcahy Symmons et al. (2023) who identified that conflict or lack of closeness and trust between the patient and family caregiver can explain disagreement in decision-making processes for treatment and care.

In the present study, family caregivers who felt obliged to care were more avoidant of being emotionally involved in patient decision-making processes than those did not feel heavily obligated to care. Such situations arose from family caregivers' inability to intuit patients' wishes without patients explicitly stating them because of their lack of mutual closeness. Family caregivers who felt heavily obligated in their role as caregiver sometimes assisted patients in their decision-making processes, but without the apparent emotional investment when compared to those who did not feel constrained by their obligation. In some situations, family caregivers' inability to correctly judge the wishes of their patients (due to the lack or insufficiency of in-depth discussions regarding the patient's end-of-life care) caused family caregivers to require patient input in all decisions. However, there were also situations where patients were unable to lead in decision-making based conversations due their physical and/or or cognitive decline, and this could make decision-making in relation to patient treatment and care difficult to navigate for family caregivers. As such, the findings suggest a need for early

family caregiver inclusion in end-of-life discussions to have the experience and knowledge necessary to adopt a proxy role in decision-making when a patient's condition has deteriorated to the point of incapacity to participate in these decisions. These findings highlight the importance of advanced care planning particularly in circumstances where conflict and avoidance during end-of-life discussions can inhibit family caregivers from acting as suitable proxy decision-makers for patients (Scott et al., 2013)

7.2.6 Patient obligation to family caregiver

Patients were also motivated to support their respective other out of both personal responsibility and obligation. Patients had differing support processes as family caregivers, as they attempted to both act in their historical supportive roles, through employing elements of support they traditionally employed prior to their illness and in the context of their new roles as now a patient and care recipient. Patients who reported close relationships with their family caregivers prior their illness appeared more able to intuit and be sensitive to the needs of their family caregivers when compared to patients who reported conflict between them and their family caregiver. Patients were also influenced by the familial relationship they had to their family caregiver, with the supportive relationship between patients who were patients and their adult children who were their family caregivers, differing significantly from that of the supportive relationship between patients and family caregivers who spouses of one another.

While family caregivers' autonomy was dependent on the actions of others, patients' autonomy was more dependent on the severity of their illness. In this way, patients did not carry much resentment towards others on their own behalf, but often disclosed that they wished for their wider family to support their family caregivers. Patients were motivated to give support to family caregivers in a way that was generally reflective of the motivations of the family caregiver. This mirrored response could be a result of patients perceiving the family caregivers' motivations through their actions. Patients' and family caregivers' experiences and responses are often so similar, described elsewhere as being in a 'double-helix' of experience (Geffen Mintz, 2014, p.1691). This

means that although patients and family caregivers may have different perspectives, they can also have inseparable needs. It is therefore understandable that patient impetus to provide support to family caregivers can be to some extent dependent on the degree to which they believe in their family caregiver desire to show support to them in the first instance. Overall, patient obligation to family caregivers was found to assist both the patient and family caregiver navigate palliative care.

7.2.6.1 Patient obligation: Impact on decision-making for treatment and care

While the present study did not reveal patients who felt solely obligated to receive support or solely obligated to provide support, there were a small number of patients who described themselves as 'stubborn' to accept support from the family caregiver. In the context of decision-making, this minority of patient participants differed to those patients who felt personally responsible to both accept support from and provide support to their family caregiver. Patients who were less accepting of support from their family caregiver tended to limit family caregiver involvement in decision-making about their treatment and care when compared to majority of participants in the study who actively involved the family caregiver in decision-making processes for treatment and care. These findings resonate with Edwards et al. (2012) who also found that some patients either strove to claim ownership and control over their illness by making decisions alone or chose to involve family caregivers directly in decision-making about care to assist them cope with their illness. Similar to findings of Edwards et al. (2012), patients who did involve family caregivers in decision-making perceived the involvement family caregivers in decision-making as a form of assistance to be appreciated.

As already outlined in the thesis, the type of relationship between the patient and family caregiver prior to the patient's illness impacted on current relations between the patient and family caregiver. In situations where there was prior mutual conflict between the patient and family caregiver, the patient felt obligated to receive care and less likely to discuss their end-of-life concerns and plans with their family caregiver. This finding is of note because the absence of communication about preferences at the end-of-life between the patient and family caregiver can lead to increased

disagreement between patients and family caregivers (Shin et al., 2015). Patients' decision to include family caregivers in end-of-life decision-making can be particularly impactful when considering its benefits on family caregivers as well as on patients. Indeed, evidence suggests that the severity of family caregiver post-traumatic stress following the bereavement of a patient is minimised when family caregivers have a pivotal role in patients' end-of-life decision making (Detering et al., 2010). The findings from the present study indicate that patients' ability and/or preference to involve the family caregiver in decision-making can be beneficial for both patients and family caregivers.

7.2.7 Forms of support between patients and family caregivers

As outlined in chapter two, findings pertaining to mutual support in previous research have come from studies where the focus at the outset of studies was not specifically on mutual support (McCauley et al., 2021). Research has highlighted the importance of examining the wellbeing of family caregivers specifically in relation to the wellbeing of the patient (Lyons & Lee, 2020; Valero-Cantero et al., 2022). These studies have found that there is a relationship between the condition of the patient and the condition of the family caregiver and they have examined whether the severity of a patient's illness will be similarly impactful to the family caregiver's wellbeing. However, while studies pertaining to the relatedness of family caregiver and patient wellbeing are relevant to the present study, few studies focus on this relationship as it affects patients responding to the condition of their family caregiver.

Previous research addresses aspects of mutual support, without naming it as such, but referring to processes which exist within it. For example, studies have captured patient perspectives of receiving one form of support, such as a family caregiver self-educating about the patient's illness or creating a calm environment, and the actions through which patients repay this support debt, through appreciation and encouragement (Lee & Bell, 2011; Norinder et al., 2017). These studies have acknowledged how these processes contribute to increased open disclosure and better shared management of future difficult circumstances. However, failing to recognise these exchanges as mutually cooperative processes invalidates the patient as a valuable member of their

family unit who can influence and ameliorate the wellbeing of their family caregivers (Liao et al., 2023). Hence, although there is research which indicates the existence of mutual support between patients and family caregivers in palliative care, these studies do not necessarily illustrate how patients reciprocate with supportive actions and behaviours.

Evidence for emotional relatedness in recent literature in addition to the evidence of mutual support embedded within related research evidenced the need for the present study. The emphasis of previous literature on patient outcomes has not always focused on how patient outcomes are influenced by family caregiver outcomes despite our knowledge that patients' psychological wellbeing impacts on the wellbeing of their families (Dubey et al., 2015; Heidari & Mardani–Hamoooleh, 2016; Körner et al., 2016). Previous research has adopted a practice of addressing how the patient and family caregiver are impacted by each other without always acknowledging the cyclical, escalating, and de-escalating nature of their responses on one another. Instead, adopting the assumption that support between the patient and family caregiver in palliative care can be bidirectional has the capacity to generate a clearer understanding of the patient and a family caregiver in the context of their relationship.

The relevance of the findings of the present study are bolstered by Colclough et al. (2023) who investigated the coping styles of patients with dementia and their family caregivers navigating illness progression in the context of the COVID-19 pandemic. Colclough et al. (2023) found that active open engagement (referred to as open disclosure in the present study), empathetic bidirectional support, and collaborative negotiation of stressful situations were positive contributors to mutually adaptive behaviours. Similarly, closed disclosure, which Colclough et al. (2023) refer to as 'protective buffering' of one another through concealment, avoidant behaviours, hostility, and overprotection of one another, contributed to maladaptive coping. These findings therefore highlight mutual support as a potential predictor of shared positive coping and of mutual ability to adapt to challenging circumstances.

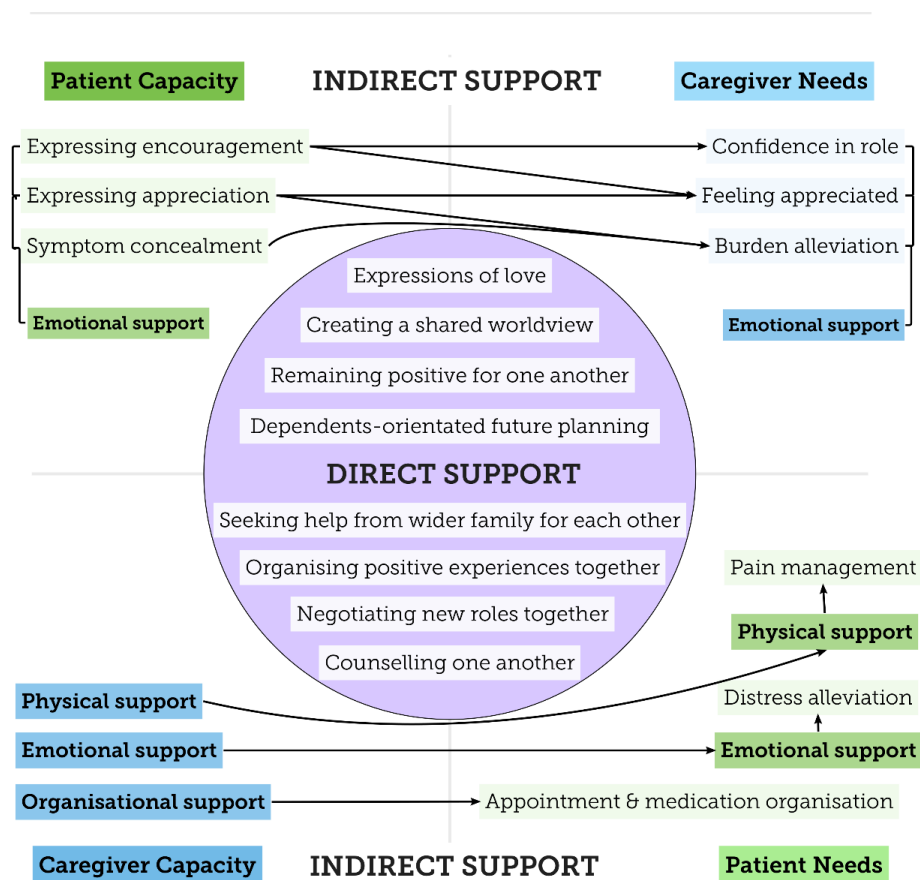
7.2.7.1 Patients as a support for family caregivers

As stated by Smith (2014, p.160), recognising patients and their family caregivers holistically as a unit of care 'acknowledges that human beings are not easily extracted from a given communal context.' Patients receiving palliative care retain the human complexities and the social roles which are carried over from their pre-morbid lives. Patients often struggle with a loss of identity, dignity, and autonomy post-diagnosis, in addition to attempting to come to terms with their imminent death (Laursen et al., 2019). This maladjustment has been theorised to be dependent on a disruption to self-concept, which occurs when circumstances require individuals to act inconsistently with the way in which they view themselves (Charmaz, 1983). A novel finding of the present study pertains to the reluctance of some individuals receiving care and treatment to become patients and be dependent on the support of their family caregivers. Some patients found adjusting to their new roles difficult for reasons dependent on their previous familial role. The present study found that patients could be resistant to receiving support due to lack of closeness with their family caregiver, perceived loss of dignity, unwillingness to accept their prognosis, inability to perform their previously held tasks and roles within their household and family, and difficulty experiencing pain, fatigue, and symptom management. The above findings are notable as they illustrate the difficulty experienced by both patients and family caregivers when patients can be expected to undertake the responsibility of being *good* patients, accepting of and grateful for support given by supportive family caregivers.

Patients attempt to manage their suffering not only for the alleviation of their own pain and distress, but also in the context of how their suffering may cause suffering in others (Smith, 2014). The diagnosis of an illness applies additional existential and social concerns to already complex individuals, yet patients are often considered solely as recipients of support from healthcare services and their families. Credence therefore must be given to patients as emotional, spiritual, and socially interconnected human beings who retain the moral bonds with other individuals which they formed prior to their illness (Smith, 2014). Patients' pre-morbid commitment to their family members does not become diluted by their diagnoses. However, the physical manifestations of this commitment that patients gave to their family members pre-morbidity can be impeded by their physical symptoms and/or physical disability. A significant finding of

the present study is the confirmation that patients can and do act in a supportive role towards their family caregivers. Previous research has asserted that patients can act in supportive roles towards other patients (Beaver et al., 2016; Kent et al., 2013). However, as stated, a dearth of research has aimed to understand the patient's role in terms of providing support to their family caregiver. This is the case despite evidence indicating patient acknowledgement of family caregiver strain (Combrink & Maree, 2016), evidence pertaining to emotional relatedness between patients and family caregivers (Northouse et al., 2012), and evidence illustrating patient ability to offer support to family caregivers in contexts beyond palliative care (Beaver et al., 2016; Goldfarb & Casillas, 2014; Kent et al., 2013). Evidence from the present study has clearly identified that patients in palliative care can function as providers of support to their family caregivers. Examples of patients and family caregivers establishing their counterparts' needs versus their own capacity can be seen in figure 9 below.

Figure 9. *Needs versus capacity in support reciprocation*



7.2.7.2 Forms of mutual support

7.2.7.2.1 Co-construction of a shared reality

A key finding of the present study is of patients and family caregivers in palliative care creating a shared view of their circumstances. This concept of co-construction of patient preferences and understanding of their circumstances is often referred to in the context of the patient-clinician relationship (Epstein & Gramling, 2013). Healthcare professionals assist patients in making decisions regarding their preferences for care and often must assess the discrepancy between the degree to which patients wish to be involved in these decisions, the degree to which they wish to fully understand the reality of their illness, and their emotional disclosure within the contexts of these discussions. It can therefore be assumed that similar approaches must be taken within the context of informal care, whereby family caregivers hold a similar role to healthcare professionals in terms of advocating for and assisting patients in their decision-making (Epstein & Gramling, 2013). While clinicians can advise the patient based on their co-construction of reality and future predictions, it is the patient's duty to ultimately select their chosen treatment plan for which they require advice from informal caregivers to feel their choice is the correct one and which is supported by those close to them. Patient and family caregiver co-construction of reality has previously been reported by Wittenberg-Lyles et al. (2011) who suggests that patients and family caregivers can better adapt to changing circumstances and fluctuations in the patient's condition if viewed from the same perspective.

In the present study, co-construction of reality contributed in a broadly positive way to the lives of patients and family caregivers with the capacity to develop a shared view, with a greater understanding of their shared expectations of their circumstances and indeed of one another. An understanding of one another, particularly with regards to the needs, expectations, and roles they expected of themselves and of one another, assisted both the patient and family caregiver in the transitional periods of the patient illness typically understood to be turbulent and distressing (Fringer et al., 2018).

Moreover, a shared understanding of the needs and wants of one another allowed for patients and family caregivers to navigate crises and feel supported by one another.

7.2.7.2.2 Co-construction in shared coping and adaption

Open disclosure was a central feature of relationships in which a co-constructed reality was created. Change in the patient condition could be followed by discussions pertaining to the reassessment of this shared reality and this involved patients and family caregivers readjusting their expectations for one another and of their relationship in the context of their changing roles and circumstances. Such discussions were pivotal to decision-making about future care for which open disclosure was essential to reach a shared consensus on a patient and family caregiver's plans for the remainder of their lives together.

Family caregivers cannot always accurately predict the end-of-life wishes for patients as illustrated in the context of palliative care for patients with dementia (Harrison Denning et al., 2016). Harrison Denning et al. (2016) found that family caregivers who struggled to discuss advanced care planning sufficiently with a patient with dementia often did not concur with their patients wishes when attempting to predict their advanced care plan. The quality of relationships between family caregivers and patients bore no effect on this prediction ability, with family caregivers showing no improved ability to predict patient wishes even in strong, harmonious relationships (Harrison Denning et al., 2016). This suggests that despite the range of benefits that accompany harmonious and strong relationships, the ability to predict the preferences of one another is highly dependent on the presence of open disclosure and the ability to candidly discuss sensitive topics as they arose. While limited evidence exists pertaining to co-construction of the patient and family caregiver narrative within the context of adult palliative care, research has identified the benefits of co-construction of reality when attempting to assist children adjust to diagnoses of chronic or life-limiting illnesses (Saltzman et al., 2013). Here, co-construction of narratives have been shown to increase meaning-making and adaptive resilience within families following injury, illness acquisition, and bereavement (Saltzman et al., 2013). Co-construction of shared realities therefore assists patients and family caregivers collectively in adapting

to distressing and psychologically straining circumstances through the process of 'making meaning' of these circumstances and adapting to their new circumstances with renewed resilience (Saltzman et al., 2013).

Previous research pertaining to meaning-making and co-construction of shared reality has been unidirectional, with the burden of meaning-making placed on parents to narrate their circumstances to their children to facilitate their children's comfort. This form of co-construction is more aligned to the 'traditional' unidirectional view of the patient and family caregiver dynamic, whereby family caregivers already occupied a family caregiving role and where the patient was a recipient of care. The findings of the present study show that patients do not need to be infantilised and can be largely adept at assisting their family caregivers in creating this shared narrative. In the case of the present context, a more equitable process can occur, namely dialectical meaning-making (Ohs et al., 2015). Dialectical meaning-making is reached when two parties, both with their own individualistic perspectives on shared circumstances compromise with each other's realities to reach consensus of a shared meaning (Considine & Miller, 2010). Creating a shared narrative is therefore a natural coping mechanism which has been found to be highly assistive in the adjustment of individuals to difficult circumstances and have been fostered and catalysed within other contexts. In conclusion, evidence suggests that even relationships that are conflictive and/or discordant prior to the patient illness can be improved with mutual understanding and adaptation (Juarez, 2014).

7.2.7.2.3 Mutually supportive communication between patients and family caregivers

A significant type of mutual emotional support in the present study was the efforts of both patients and family caregiver to communicating with one another in emotionally challenging conversations. The most mutually supportive and equitable relationships reported by participants in the present study had the ability to carefully navigate these conversations in order to maintain open disclosure whilst at the same time, attempting to reduce the likelihood of upset and distress for their respective other. An important factor to note is that these conversations were often challenging with family caregivers

attempting to suppress discussing their own desire for the patient to attempt to extend their life whilst having to advocate for the patient's wishes, even if these wishes would accelerate the patient's death. In this way, providing support to one another was also challenging because patients and family caregivers reported that their emotions were heightened as they attempted to remain rational and make the 'correct decision' in conversations they both perceived to have life-changing consequences.

Open conversations between patients and family caregivers also facilitated each other's ability to be more intuitive about each other's needs because both the patient and family caregiver discovered information about one another which could then inform future supportive behaviours. When a patient or family caregiver responded well to a particular communication style within these conversations, their respective other could utilise this communication style in future conversations, making conversations less effortful and more comfortable than the experience might otherwise have been in the absence of open communication and discussion about patient treatment and care. Both compassion and empathetic within these contexts also allowed open disclosure to be fostered between both patient and family caregiver, with both parties perceiving that they were being heard and considered. When these conversations were reported by participants to be frequent, patients and family caregivers felt considerably more comfortable and adept in discussions with one another about patient care knowing that they have been heard by one another and considered in previous difficult conversations. This finding is concurrent with previous research in the field (Wallace, 2015).

Mutually supportive relationships in the present study were characterised by open disclosure, most often observed between patients and family caregivers who were spouses. Open disclosure has been found to facilitate difficult conversations in the face of life-limiting (Carmel et al., 2020) and non-life limiting illness (Jeyathevan et al., 2019), which itself is facilitated by shared comfort and mutual compassion within discussions about treatment and care (Milbury & Badr, 2013). Open disclosure in the present study was also present in parent-adult child caregiving relationships. However, these participants reported having to overcome historical and familial role related obstacles in order to communicate frankly with one another. In addition to the benefits

of open disclosure in assisting patients in making decisions which they feel are supported, open disclosure also has been found to significantly reduce feelings of burden in family caregivers in the context that family caregivers endured less effort in communicating with patients (Shin et al., 2016; Shin et al., 2018). This finding is concurrent with the present study whereby family caregivers reported the positive effects of open disclosure, citing ease of communication as a basis not only for intimacy with and trust in their ill family member, but also for shared decision-making with respect to the patient's treatment and care. The findings of the present study highlight the need for patient and family caregiver mutual expression of emotional support and mutual safeguarding of one another in conversations pertaining to treatment and care.

7.2.7.2.4 Expressions of emotional support between patients and family caregivers

Expressions of emotional support among participants in the study included both verbal statements of gratitude, encouragement, affection, appreciation, admiration, and love in addition to physical behaviours and gestures that could convey the above.

Expressions of mutual support between patients and family caregivers cope with the challenges of life-limiting illness. These findings are consistent with those of Nipp et al. (2016) who also found that mutual support in the form of emotional support was an effective coping strategy for patients and family caregivers. Expressions of mutual support and concern between patients and family caregiver in palliative care have been found to affirm and bolster relationships and assist patients and family caregivers to forgive historical discordance and conflicts (Prince-Paul et al., 2013). In the present study, the findings suggest that reciprocation of emotional support between patients and family caregivers in palliative care has the potential to alleviate the effects of historical conflict between patients and family caregivers.

The present study has identified the importance that both patients and family caregivers in palliative care attach to the expression of emotional support between them. However, both patients and family caregivers also reported exhibiting behaviours which constituted latent expressions of affection and concern aimed at ameliorating their shared lives. These behaviours included attempts at maintaining

normality for one another to alleviate distress for one another, but also concealing their distress or symptoms from one another when perceiving burden in their respective other.

7.2.7.2.5 Patients and family caregivers seeking to maintain normality

The present study revealed that both patients and family caregivers took great solace in the ability to experience elements of normality in their everyday lives. In observing the positive effects that normality had on their respective other, both parties would then attempt to simulate normality as best possible as a form of support for one another. This is consistent with previous research which found that patients and family caregivers attempt to create a sense of normality by engaging in everyday activities (Berterö et al., 2008). Patients also most often chose to remain at home to receive palliative care, while also acknowledging the additional strain this choice would place on their informal caregivers, which illustrates the prioritisation of a shared normality over burdening or being burdened by the additional care tasks. This finding is consistent with other evidence which indicated that the primary motivation for remaining at home through the course of receiving palliative care is the maintenance of normality in a time of uncontrolled and unpredictable circumstances (Appelin et al., 2005). Patients that wanted to be cared for by family members throughout their period of illness did so as being cared for primarily by family further maintained normality. However, this was dependent on family caregivers' and patients' ability to retain their normal dynamic, which in of itself was often challenging in the face of stressors including increased symptom severity of patients and the additional responsibilities assumed by family caregivers.

A significant obstacle for patients and family caregivers in the present study to maintain normality was the marked difference between the daily life of a patient and family caregiver give sudden and sometimes unexpected deterioration in the patient's illness. Whilst some family caregivers did refer to the monotony of their daily lives in which they mourned the loss of their previous lives, they also found themselves bracing for sudden and/or rapid change in circumstances. This cycle from period of perceived monotony to periods of high stress and then back to perceived monotony

caused patients and family caregivers to be in a near constant state of unease. Being in a state of constant unease made it then somewhat more difficult for patients and family caregivers to maintain a sense of normality in their lives. These findings resonate with those of Duggleby et al. (2010) who also found that seeking to maintain normality was difficult for patients with advanced illness and their family caregivers as they transitioned to different stages of care and stages of the patient's illness.

In the present study, a significant indicator of patients' and family caregivers' desire to maintain normality in the present study was the attempt by patients and family caregivers to (re)define their roles as they related to their respective another. Family caregivers generally attempted to retain their previous employment for as long as possible, supported by patients where the relationship was reported to be strong by patients and family caregivers. Patients also attempted to retain some of their previous responsibilities in the family, whether resorting to completing small, tokenistic tasks such as lighting the fire or making the family caregiver a cup of tea, or solely retaining the emotional support they offered to family members prior to their illness. Patients played a significant role in the retention of normality which has been under-reported in the literature. While previous research (Judd et al., 2019; Kirby et al., 2014; McLaughlin et al., 2011) refers to the stoicism of family caregivers in masking elements of their distress for the patient, several patients in the present study also referred to their attempt to mask their own strain to retain normality for their family caregiver. Indeed, several patient participants in the present study wished to appear well for their family members so as not to cause distress for their family members. These findings resonate with those of Horne et al., (2012) who found that patients strove not to 'burst the bubble' (Horne et al., 2012, p. 722) of their family members who retained unrealistic hope that the patient might somehow convalesce and recover from their illness. A fine line separated patients from concealing just some elements of their experience which they perceived would be harmful to their family caregiver and fully concealing their distress and/or concerns. Patients successfully concealed the severity of their symptoms but remained open about their distress and/or concerns when they felt it was a supportive behaviour towards their family caregiver. Importantly, supportive relationships between patients and family caregivers were heavily reliant on

how trusting family caregivers were in the patient's account of their experience, and as a result patients had to mask modestly their distress and/or concerns to maintain open communication between them and their family caregiver.

7.2.7.2.6 Mutual concealment between patients and family caregivers

Patient and family caregiver concealment could act as a barrier to or a facilitator of mutual support between the patient and family caregiver, and which is discussed further in section 7.2.8.5. This section (7.2.7.2.6) focuses on the supportive intentions behind acts of concealment and the intentioned beneficial effects that were reported by participants.

The results of the present study highlighted the two outcomes that could arise from concealment. Dependent on the degree to which receiver's ability to see the reality of the situation, thus disbelieving the concealment, or was oblivious to the masking of symptoms or distress, thus being unaware of the concealment, concealment acted as a successful salve for distress or acted as a further contributor to distress. As such, the concealment itself was not the factor that altered the dynamic between patient and family caregiver, but the degree to which the individual to whom the concealment was directed could see through the attempt.

It has been identified by Schaepe (2011) and Van Humbeeck (2019) that patients and family caregivers can attempt to 'soften the blow' of perceived bad news within discussions pertaining to illness and care, particularly when their relationship prior to the patient's illness consisted of a perceived 'stronger' and a perceived 'sensitive' person in the relationship. In the present study, patient and family caregiver concealment was used with the intention of benefiting and safeguarding the mental psychological functioning of their respective another. Yet, this behaviour also manifested when patients and family caregivers were attempting to avoid partaking in difficult discussions due to their own discomfort about their circumstances. Such concealment can manifest as omission or nondisclosure of information rather than direct dishonesty (Möllerberg et al., 2017) and this nondisclosure has been typically viewed as negative (Martín-Forteza et al., 2020; Pinyopornpanish et al., 2017). However, the aforementioned studies predominantly relate to nondisclosure of diagnostic

information, with some patients and family caregivers withholding diagnoses and prognoses from their counterpart, influencing the course of decision-making and ultimately resulting in a loss of perceived control and autonomy for both patients and family caregivers (Alsirafy et al., 2017; Machado et al., 2019).

Concealment, and the belief or disbelief of it, was considered to act as either a barrier or facilitator in the present study, dependent on the circumstances in which it functioned. This is a novel finding, as a priori literature has exclusively discussed concealment as having a negative effect. The present study, however, while acknowledging that concealment often had a detrimental effect on the trust and transparency between a patient and family caregiver when discovered, was typically undertaken with caring, safeguarding intentions.

7.2.8 Barriers to and facilitators of mutual support between patients and family caregivers

As presented in detailed in chapter five, multiple factors enabled and inhibited mutual support between patients and family caregivers. Due to the complex and fluctuating nature of the palliative care experience for both patients and family caregivers, patients and family caregivers wants and needs from each other could change at different points in the palliative care experience. As a result, some factors that may have acted as facilitators of mutual support between patients and family caregiver at certain times could act as barriers to support at other times. For example, the presence of a large number of family members who wished to give input into decision-making could be both a facilitator and barrier to mutual support between patients and family caregivers. In addition, the intentions behind patients and family caregiver behaviours to be supportive could act as a barrier or facilitator to mutual support as was the case for mutual concealment between patients and family caregivers. It is therefore important to understand the patient and family caregiver dynamic depicted by not only tensions but also contradictions.

There is evidence that tensions do not only occur between patients and family caregivers in a dyadic context, but that they also manifest out of individualistic conflicting needs and wants of both people. A study by Oetzel et al. (2015) found that

common tensions experienced by patients and family caregivers were the conflicts in prioritising autonomy or shared experience, connection or conflict, isolation or connectedness, and self-care or family-based care. These tensions, compounded by family caregivers' internal dissonance of being both a primary family caregiver and a member the unit of care, and patients' dissonance in consolidating their pre-morbid lives with their lives since their diagnosis, resulted in a complex, unsettling, and distressing experience for both patients and family caregivers. Benkel and Molander (2015) note that patients and family caregivers can struggle balancing between their individual needs and understandings with the needs that are more representative of the patient and family caregiver unit. In the present study, some behaviours and actions of patients and family caregivers could be both supportive and restrictive.

7.2.8.1 Patient and family caregiver dyadic coping

As stated in chapter five, creating a mutual understanding, reached through compromise of each party's own view of their circumstances, was pivotal for both the patient and family care to sufficiently understand one another, be intuitive about each other's needs and wants, and to make decisions in the interest of one another. These behaviours fall under the category of shared dyadic coping, which manifested within the relationships of the participants in different forms and to different degrees of success. The evidence on shared dyadic coping is robust (e.g., Greer et al., 2020; Liljeroos et al., 2021; Van Roij et al., 2022). Falconier and Kuhn (2019) synthesised over 20 years of evidence on dyadic coping to develop a theoretical model to explain dyadic coping. Their review found mixed results, with some studies stating that similarity in coping styles in couples was beneficial while other studies implied that difference in coping styles resulted in improved problem-solving for each member of the dyad. Falconier and Kuhn (2019) surmised that overall, a shared coping style was generally beneficial to a dyad irrespective of the individual coping styles of each member of the dyad. In the context of the patient and caregiver relationship, trust and belief in one another can bolster mutual support between the patient and caregiver because the very nature of the connection between the patient and caregiver means that each has the potential to benefit from one another (Geffen Mintz, 2014).

7.2.8.2 Family-based roles of patients and family caregivers

Family-based roles acted both as both a barrier to and a facilitator of mutual support between the patient and family caregiver and were heavily shaped by the type of familial connection between the patient and family caregiver and by the quality of the relationships that the patient and family caregiver reported prior to the patient's illness. Previous research has highlighted the success of reciprocal relationships over authoritative relationships in terms of avoiding conflict and retaining dignity of both family caregivers and patients at end-of-life (Chan et al., 2012). Family caregivers often struggle with their dual roles as members of the unit of care in the eyes of healthcare professionals and as the primary providers of informal care (Benkel & Molander, 2015). In addition to this dichotomy, family caregivers can also find difficulty in maintaining their previous, often more submissive familial roles in tandem with their supervisory family caregiver roles (Trees et al., 2017). In the present study, family-based roles for family caregivers were accompanied with expectations of performance from other family members, which could facilitate or inhibit the performance of a family caregiver in their caregiving role.

The differences between patients and family caregivers who were spouses, and patients and family caregivers who were parents and adult-children respectively, was significant particularly with regards to motivations to support, role transition, the historical caregiving dynamic and the expectations placed each on one another. Previous research has indicated the interconnectedness of spousal dyads, which influences the way in which they approach a diagnosis of a life-limiting illness (Li & Loke, 2013), with couples likely to approach a diagnosis as an 'emotional system' (Hagedoorn et al., 2008) in which they have synchronous responses and interdependent satisfaction scores at different junctures in palliative care (Samios et al., 2014). The present study found that spousal patients and family caregivers who perceived that they are 'equals' prior to the patient's diagnosis shared advantages of the spousal relationship which included prior experience in shared decision-making, constructing a shared reality and having supported one another prior to the patient's illness.

As outlined in the present study, patients who were parents and where their family caregiver was their adult child often found the adjustment to their new roles more difficult when compared to patients and family caregivers who were spouses. In cases of the former (i.e., where the patient was a parent of their adult family caregiver), exchanging roles of care recipient and care provider was made difficult by the habitual behaviours that had carried over from patients and family caregivers' previous dynamic as parent, natural caregiver, and child, natural care recipient. In the present study, family caregivers who were adult children, regardless of age, often referred to themselves as the 'baby' of the family which they felt inhibited them in garnering respect from their parent in their now changed role as care provider to their patient parent. These findings are concurrent with a qualitative study by Ohs et al. (2015) in which family caregivers felt that their role as stakeholders in decision-making regarding the patient's care was undermined as a result of the role that had occupied prior to assuming a primary caregiver role. In the present study, some patients who were parents could be demanding of their adult-child caregiver as they too retained certain dynamics of their previous relationships such as freely instructing their adult children on tasks and responsibilities.

In the present study, the existing cultural context of the family also shaped the experience of both the patient and family caregiver. The way in which the patient had provided care to the family caregiver earlier in their shared lives influenced the way in which family caregivers assumed their caregiving roles. If patients had previously provided historical care to family, for example to their own children or to their own parents, there was a cultural expectation within the family for the adult child of a patient to eventually become a family caregiver to the patient. This finding links with the key concept of obligation and personal responsibility, dependent on how this mechanism has functioned in each type of relationship. This finding can be understood by examining the Acceptance Theory of Family Caregiving (Feliciano et al., 2022). This theory states that if a parent patient has promoted a culture of caregiving in the family environment, the likelihood of their children adopting family caregiving roles will be increased, with this culture also influencing family caregivers' physical, economical, psychological, and spiritual responses to their circumstances.

The Acceptance Theory of Family Caregiving implies that the context surrounding the adoption of a family member's caregiving role influences the quality and type of care received by patients from family caregivers. Hence, this theory implies that the *exchange* of support, in this case historical care for present-day care, is impactful on the readiness, sense of autonomy and acceptance with which family caregivers assume their caregiving roles. Family caregivers who perceive that they have a choice in adopting their roles have a greater quality of life than those who feel obligated in assuming their roles. This theory would suggest that those who perceive they have 'chosen' family caregiving have been primed to make this decision based on the historical behaviour of the individual for whom the now family caregiver provides support to. In the present study and consistent with a study by Williams et al. (2014) which explored caregiver experiences, family caregivers' willingness to assume a caregiving role was influenced heavily by their relationship with the patient prior to the patient's illness and by how the patient had previously supported the family caregiver. These factors (i.e., prior relationship between the patient and family caregiver, historical context to caregiving within the family) can impact on the family caregiver's role satisfaction and adaptability (Kim et al., 2015; Kyei-Arthur & Atobrah, 2022), and on a patient's role satisfaction, security, and perception of themselves as burdensome (Sun & Francis, 2024; Francis et al., 2010).

7.2.8.3 Support provided by the wider family to the patient and family caregiver

The presence of support from the wider family to the patient and family caregiver in the present study was a facilitator of mutual support between them. The majority of patients and family caregivers did not perceive that they were receiving sufficient support from their wider families. This is concurrent with other research in palliative care on patient and family caregiver decision-making (Dionne-Odom et al., 2017). However, it must be noted that a family caregiver's perceived lack of wider family support does not necessarily indicate that there is a lack of wider familial support, but rather indicates that the support offered by the family is deemed to be insufficient by family caregivers (Ozdemir et al., 2021). Nonetheless, patients and family caregivers in

the present study stated their satisfaction or dissatisfaction with the amount of support they were receiving from the wider family. Some were satisfied with a small number of visits per week, and some were dissatisfied, expecting more regular support. Despite receiving the same amount of support, the way in which the support was appraised was influential on whether this support acted as a barrier to or a facilitator of mutual support. The present study found that a lack of support from the wider family could impact negatively on patient and family caregiver mood and wellbeing. These findings are supported by other evidence in the field (Benson et al., 2023).

In a study of the correlates of family conflict by Kramer and Boelk (2015), only 9% of families who experienced conflict at their ill family members' end of life did not have discordant familial relationships. According to Hamano et al. (2022), the primary cause for family conflict within the palliative care context can be about concerns over other family members not providing sufficient support to the patient and family caregiver. Hamano et al. (2022) found that perceived family functioning was highly correlated with family conflict, indicating that the functioning of the family prior to the patient's illness was influential on their ability to cope and cohere with the palliative care experience. Indeed, Boelk and Kramer (2012) found that in addition to this limited support, some family caregivers were left frustrated when other family members were asserting control in a dynamic which had not previously involved them. In the present study, patients and family caregivers reported that the wider family appeared to function well when the family was a close unit before the patient's illness. In these cases, other family members could enable support between the patient and family caregiver.

In the present study, it was noted that patient and family caregiver perceived lack of support from the wider family meant that the family caregiver had to leave other family duties to provide sufficient support to the patient. This caused not only feelings of distress for family caregivers but also feelings of isolation and resentment. These findings resonate with those of Wittenberg-Lyles et al. (2014) who identified similar feelings among family caregivers when unsupported by the wider family in their caregiving role. However, feelings of isolation and distress for the patient and family

caregiver in their relationship can also be perpetuated by the manifestations of denial within the wider family (Benson et al., 2023). Notably, previous studies have found that a lack of support from the wider family can lead to patients deciding to cease treatment because of the extra family-based support that they might need because of proceeding with specific treatments (Pisaturo et al., 2017). A lack of support from the wider family has also shown to correlate with patient and family caregiver discordance in treatment decisions, which contributed to patient and family caregiver distress and inhibited mutual support because of conflict (Ozdemir et al., 2021). Lack of access to wider family support is also known to impact on the patient's preferred place of death, as the dearth of appropriate candidates to support a patient's wish to die at home results in patients often dying in hospital against their wishes. Consequentially, members of these families with reduced support are often the obliged family caregivers, who adopt their roles in the absence of other candidates, often experiencing resentment at both the lack of support from the wider family but also obligation to facilitate care at home in accordance with the patient's wishes (Woodman et al., 2016).

7.2.8.4 Closeness and mutual loss between the patient and family caregiver

Whilst relational connectedness was broadly a facilitator of mutual support, instances occurred whereby closeness between the patient and family caregiver could impact adversely on the autonomy of both the patient and family caregiver. Some patients reporting refusing care from anyone but their primary family caregiver, which in some cases was perceived by family caregiver to impact adversely on their own autonomy because it limited their freedom to attend to their own self-care. Patients' autonomy was in some cases, also infringed upon by closeness between them and their family caregiver when the family caregiver was reluctant to leave the patient's side due to fear of incident in their absence even if the patient preferred on occasions their own company alone. This finding is consistent with that of Herbst et al. (2022) who also found that the continuous presence of caregivers prevented patients from spending time alone.

Additionally, despite close emotional relatedness facilitating several other aspects of mutual support, most significantly intuitive care, the degree to which a patient and family caregiver were emotionally close to one another exacerbated feelings of pre-bereavement and mutual loss between them. Those who felt less constrained by their roles, due to similar closeness pre-morbidity, were often unable to experience enjoyable shared experiences and memory-making activities due to the significant sense of pre-bereavement that underlined these experiences. A dearth of a priori literature exists pertaining to the shared nature of pre-bereavement, between patients and family caregivers. Little consideration has previously been given to the sense that patients are also anticipating a loss, despite understanding that they would not have to experience life without their counterpart. While research pertaining to the 'loss of self' of patients at end-of-life has been undertaken (McClement & Thompson, 2018) this refers to the loss experienced on observing the gradual ebbing away of one's personhood, with little consideration of those whom the patient is losing through their death. Thus, this pre-bereavement has previously been understood to be solely experienced by the family caregiver, and not the patient themselves. The concept of mutual pre-bereavement is therefore a novel finding that requires further exploration.

7.2.8.5 Patient and family caregiver concealment

As outlined in the findings, patients and family caregivers in the study took part in acts of concealment for a range of reasons. Some patients were well-intentioned, and while being transparent regarding their diagnoses, details of healthcare meetings, and feelings on treatment options, they reported concealing or at least understating the severity of their symptoms to reduce family caregiver burden. Similarly, family caregivers reported that they attempted to conceal their own distress to the patient to protect the wellbeing of the patient. These small acts of concealment by patients of their symptoms were intended by patients to be of benefit to the family caregiver. This finding does not concur fully with the literature which typically accounts for such behaviours as maladaptive or negative coping strategies (Lemus-Riscanevo et al., 2019; Tuca et al., 2021).

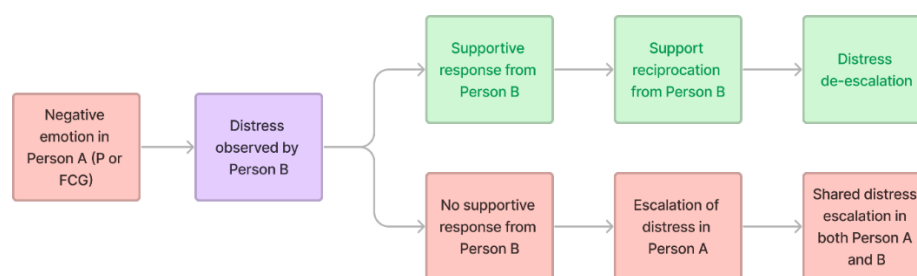
More recent research has established that the motivations behind omission of information is often well-intentioned, and not carried out with the intention to harm the patient, in the case of family caregiver concealment, or the family caregiver, in the case of patient concealment (De la Piedra-Torres et al., 2022). Patient and family caregiver concealment reported by De la Piedra-Torres et al. (2022) included non-disclosure of medical information to one another, understating the seriousness of the overall condition to each other, hiding the reality of the prognosis from each other, and making decisions about care without consulting one another (Lütgendorf-Caucig et al., 2015; Nipp et al., 2016). In the present study, patient and family caregiver concealment was with the intention of for the other. In addition, some patients concealed not just to unburden family caregivers, but also to unburden themselves from having to accept support which they needed from their family caregiver. Patients' concealment in the above dynamic further exacerbated their family caregivers' feelings of loss of control and autonomy. Consistent with a study by Horne et al. (2012) on how patients and family caregivers maintain integrity in the face of death, family caregivers in the present study were apprehensive to approach these topics because of their fear of upsetting the patient. However, patient concealment caused their family caregivers to feel unease because of being unable to discuss their own feelings with regards to the patient's condition. Similar to findings from Horne et al. (2012), patient concealment could make family caregivers unsure of how to approach their caregiving role and of the degree to which their efforts were helpful or not to the patient.

7.2.8.6 Emotional contagion between patients and family caregivers

Patients and family caregivers who reported a shared perspective were more heavily influenced by each other's emotional state than patients and family caregivers that held different perspectives from one another. Those who partook felt they had co-constructed their perspective more frequently experienced an emotional contagion-like phenomenon, by which patients and family caregivers stated that their emotional state was dependent on the emotional state of their respective other. Emotional contagion is known to occur in interdependent relationships, such as that of patient and family caregiver, whereby one or both parties mirror the nonverbal behaviours of

one another, often escalating this emotion in the individual originally externalising the emotion (Deng & Hu, 2018). The process of emotional contagion is illustrated in figure 10 below. These collective emotional experiences have been identified already in both palliative and non-palliative oncological research where patients and family caregivers disclosed their experiences of emotional congruence (Northouse et al., 2012; Yao et al., 2022).

Figure 10. *The process of emotional contagion*



There is evidence that mutual responsiveness between patients with cancer and their family caregivers can be heightened by the emotions induced by having and/or living with cancer (Yao et al., 2022). Research has focused on concurrence of family caregivers with patient emotions, particularly on the escalation of family caregiver distress in observing the distress of the patient (Coelho et al., 2020). A meta-analysis of distress of couples coping with cancer conducted by Hagedoorn et al. (2008) found that there was no significant difference between distress experienced by patients and distress experienced by family caregivers thereby suggesting that the response of both patients and family caregivers is so intrinsically linked that the same or at least very similar reaction occurs in both to external stressors. This interconnectedness provides explanation for relationship strain, whereby patients and family caregivers influence each other's emotions by becoming irritated when perceiving their counterpart to be excessively critical, demanding or negative (Rook, 2015). These traits often manifest in an individual experiencing distress, causing a response in the individual being demanded upon or criticised, and are further escalated by these confrontations (Ando

et al., 2019). This cyclical process is often observed in cases where patients and family caregivers are experiencing hopelessness, strain and burnout, which inhibits them from applying problem-focused coping (Tokem et al., 2015).

Research has identified the increased likelihood of family caregiver distress when exposed to the distress of the patient to whom they provide care (Northouse et al., 2012). However, less is known about how patients reciprocate with respect to their family caregiver's distress. In the systematic review conducted by the author (McCauley et al., 2021), only three studies pertaining to distress experienced by patients in response to their family caregiver's distress were identified over a period of 20 years (Ando et al., 2019; Badr & Taylor, 2006; von Heymann-Horan et al., 2019). The findings of the present study are novel because they illustrate that patients can mirror their family caregiver's emotional state. Of note, the findings of the present study indicate that in the absence of a secure and already strong relationship, patients and family caregivers can be less able to cope or assist each other in coping, both becoming highly burdened and feeling in conflict with or being avoidant of one another. In the case of the present study, family caregivers often felt highly burdened due to their obligation to continue to perform supportive acts for their patients even during periods in which patients dismissed or minimised family caregiver distress. These findings resonate with those of Leroy et al. (2016) on crossed views of burden and emotional distress of cancer patients and family caregivers during palliative care.

In the present study, some patients resisted support from their family caregiver because they struggled to come to terms with their life-limiting illness and in some cases, with change in roles. Subsequently, patients' feelings of both resentment and distress in some cases, caused distress for family caregivers. As stated in chapter five, discordance between patients and family caregivers and escalation in emotional distress for both the patient and family caregiver were obstacles to mutual support between the patient and family caregiver. Similar findings have been identified in a study by Von-Heymann Horan et al. (2019) which reported on dyadic coping in a specialised palliative care intervention for patients with advanced cancer and their caregivers. Overall, in the present study, escalation of negative emotions towards one another in the presence of shared distress was observed more in relationships where

patients and family caregivers did not report a strong bond with their respective other and where patients struggled to accept and/or were avoidant of support from their family caregiver.

Whilst research has focused on co-escalated negative emotions (Caserta & Gritti, 2018, Jacobs et al., 2017b), of note, shared escalation of positive emotion was also observed in the present study. Patients and family caregivers could in the context of close and agreeable relationships, foster positivity within their relationships by encouragement of one another, displaying affection and gratitude to each other, and allocating time in which to undertake shared activities that were enjoyable for both. Previous studies have identified that a primary need for patients and family caregivers was to remain broadly positive and optimistic for themselves and one another throughout their shared experiences of palliative care and of life in general (Bužgová et al., 2014; Lalani et al., 2018; McCauley et al., 2021; Vilalta et al., 2014). The present study identified some family caregivers who appeared to be experiencing more burden and distress than the patients for whom they cared for. On observing this distress in family caregivers, patients were often more concerned for their family caregivers than for themselves. When patients and family caregivers reported already having had a strong supportive relationship, the relationship was a firm basis for addressing and responding effectively to the negative emotional state of their counterpart by attempting supportive acts in response to their counterpart's negative emotions.

7.3 Chapter conclusion

This thesis thus far has shown that mutual support between patients and family caregivers in palliative care is underpinned by the nature of the relationship between the patient and family caregiver prior to the patient illness, patient and family caregiver compatible coping styles, the presence of support from the wider family including a shared satisfaction with support from the wider family, and the opportunity for both patients and family caregivers to exercise autonomy in their relationship with one another. Mutual support involves the patient and family caregiver adapting jointly to challenging circumstances. Mutual support between patients and family caregivers in palliative care is shaped by the specific nature of the familial relationship between

the patient and family caregiver (for example, spousal relationships, or parent – adult child relationships) and by the life stage of both patients and family caregivers. All the above factors impact directly and/or indirectly on how patients and family caregivers make decisions about palliative care.

The collection of these novel findings was reliant on the grounded theory methodology, allowing the researcher to identify and develop codes and concepts into categories grounded in the experience of the participants in the present study. These findings have formed a nucleus around which future interventions and frameworks can be developed. The richness of data required to form this foundational nucleus benefitted from the in-depth exploratory nature of grounded theory methodology.

The next and final chapter (chapter eight) is the concluding chapter of the thesis. The concluding chapter first surmises the key findings and points of discussion in the thesis, and then outlines a set of recommendations for future research and practice based on the findings presented in the thesis.

Chapter 8: Conclusions: Implications for Research, Policy, and Practice

Chapter 8: Conclusions: Implications for research, policy, and practice

8.1 Introduction

This study has provided evidence on what constitutes mutual support between patients and family caregivers, and the factors that facilitate and/or restrict mutual support between patients and family caregiver in palliative care. The study has also identified and explained how mutual support between patients and family caregivers in palliative impacts on their decision-making for care. The study is evidence that patients and family caregivers in palliative care can provide support to each other. Of note, the evidence points towards how feelings of obligation between patients and family caregivers can inhibit open disclosure and expressions of emotional support and affection between patients and family caregivers, and which can in turn increase family caregiver burden and foster family caregiver resentment towards other family members.

The study has reported and explained how mutual support can be understood in two main forms; that is direct and indirect. Direct mutual support occurred when patients and family caregivers reciprocated by providing similar types of support to one another and which manifested primarily as various forms of emotional support. Indirect mutual support occurred when patients could not reciprocate in supportive behaviours that required undue physical exertion or mental exertion and compensated for such by providing emotional support in lieu of other supports they felt no longer able to provide to their family caregiver (McCauley et al., 2023a). Key factors which facilitated mutual support between patients and family caregivers included strong pre-morbid relationships between patients and family caregivers, autonomy in both patient and family caregiving roles, and the support of the wider family, particularly with respect to providing respite to family caregivers (McCauley et al., 2023c). Ultimately, any factor which offered patients and family caregivers a feeling of choice, flexibility or autonomy enabled mutual support between them. Conversely, barriers to mutual support between patients and family caregivers were factors or conditions that reduced control for both the patient and family caregiver and increased burden in both their lives. Key barriers included relationship conflict between the patient and family caregiver, a lack

of wider family support for both the patient and family caregiver, and the obligation and constraint that both patients and family caregivers felt in their respective roles and in relation to one another.

As already outlined, patients often reciprocated family caregiver support by involving them in the decision-making process for treatment and care. Patients' invitation to family caregivers to partake in decision-making with patients was typically accepted with gratitude and relief from family caregivers because family caregivers were then able to regain a sense of control over their circumstances and feel they had a role in the decision-making process in relation to their shared future with the patient (McCauley et al., 2023b). However, patients who felt obligated to their family caregiver seemed less likely to involve family caregivers in decision-making processes. In contrast, patients who were comfortable in accepting care from family caregivers were eager to involve family caregivers in decision-making, with some patients even wishing to relinquish control in decision-making to family caregivers.

Understanding how the patient and family caregiver relationship functions in the context of mutual support provides a foundation on which dyadic interventions focused on patient and caregiver inter-relatedness and communication can be built. The findings of the study serve as a basis for the development of dyad-focused interventions to foster open communication and trust between patients and family caregivers, through which patients and family caregivers can understand how their actions and decisions impact on one another within the patient and family caregiver unit of care. The majority of studies on dyad-centric interventions have yielded broadly beneficial results for both patients and family caregivers, however these studies have primarily focused on patients with cancer and their family caregivers (Hu et al., 2019). The results of the present study can assist in supplementing and expanding current dyadic interventions, such as the Dyadic Cancer Outcomes Framework (Thompson et al., 2021) and the ENABLE III randomised control trial (Dionne-Odom et al., 2015) to meet the needs of all patients and family caregivers with palliative care needs, outside of cancer related illness. Additionally, the novel findings of the present study such as the delineation between personally responsible and obliged caregivers and the potentially positive effects of concealment offer new

complex insights into the patient and family caregiver dyadic dynamic which may cast light on those for whom pre-existing dyadic interventions are functioning optimally.

Positive relations between patients and family caregivers in the study featured in relationships where there was mutual disclosure and open communication about both patient and family caregiver distress, when the patient and family caregiver sought to reassure one another, and when both the patient and family caregiver considered the wellbeing of one another in the decision-making process for care. Patient and family caregiver relationships with the abovementioned features assisted the patient to understand their choices about care and helped family caregivers to self-educate regarding the patient's condition and care options to advocate for the patient to the best of their ability. In the absence of the above relations, patients and family caregivers indicated that they struggled with their perceived responsibilities to one another, particularly outside of core duties of care. A lack of collaborative decision-making, open disclosure, expressions of affection and appreciation to each other, and advocacy the part of one another, points to how health and social care professionals may need to be more routinely integrated within the patient and family caregiver unit to sustain awareness among patients and their family caregivers of each other's needs and preferences for care.

The present study has identified and described key processes and components of mutual support between patients and family caregivers in palliative care that have not been previously investigated or discussed. Factors such as the influence of the perception of autonomy on constraint within the supportive role, the effect of volunteerism to the caregiving role, the sufficiency of emotional support in reciprocating other means of support, and the use of concealment as a means of support, for example, are novel concepts that the present study has cast light upon. These components, pivotally, contribute to, and indeed contests, some of the pre-existing theoretical and conceptual frameworks that pre-exist the present study. The present chapter will discuss these novel concepts as they pertain to future research, and their implications for policy and practice.

8.2 Implications for research, policy, and practice

8.2.1 Implications for research

The findings of the study reveal a need for the consideration of the presence or absence of mutual support when examining the psychosocial wellbeing of both patients and their family caregivers in palliative care. The topic of mutual support requires closer examination namely the influence of pre-morbid relationships on relationship functioning between patients and family caregivers, the role of autonomy for both patient and family caregiver in decision-making, the opportunity for respite for both patient and family caregiver, and the impact of the wider family on the patient and family caregiver relationship. Further investigation into these central features of mutual support would be beneficial to expand and substantiate the findings of the present study. This section (8.2.1) outlines the implications of the findings of the study for future research.

First, it must be noted that the findings of the study come from a sample of patients and family caregivers where caregivers were limited to spouses/partner and adult children. However, it is understood that family caregiving exists outside of spousal relationships, and with the definition of family caregiver extending to family caregivers who are siblings, siblings-in-law, nieces and nephews, and friends in previous research (Bruton et al., 2023; Vidal et al., 2022). Indeed, we know that substantial informal caregiving in palliative care is provided by people beyond spouses, formal partners, or indeed blood relatives (Burns et al., 2013). The lack of these other categories of caregivers in the sample was not a result of exclusion, but perhaps an indicator of who primary caregiving may fall to particularly in the context of the age and life stage of patients who participated in the study. The perspective of other categories of family caregivers should be represented in future research to ensure that studies do not neglect the experience of caregiving in palliative care outside beyond the spousal relationship or blood relatives.

Second, while the sample of patient and family caregivers varied along a number of other dimensions (as detailed in chapter three), the study captured the patient and

family caregiver experience primarily with patients who had advanced, metastatic cancer and their family caregivers. Further research on the processes of mutual support between patients and family caregivers in palliative care should ideally recruit patients who vary with respect to their diagnosis and who ordinarily receive palliative care (i.e., patients with diagnoses other than cancer). The development of future interventions focused on supportive relationships between patients and family caregivers intended to accommodate multiple diagnostic groupings of patients and their family caregivers would need to account for such variation.

Third, the findings of the present study as they pertain to patient and family caregiver (in palliative care) motivations to contribute to mutually supportive relationships with their respective other are novel. A sense of obligation arose in cases where patients and/or family caregivers were resistant to their new circumstances and when they felt that they had no choice or autonomy within their new roles. Resistance to providing a substantial amount emotional support to one another outside of the compulsory acts of giving or receiving of physical support to one another featured among patients and family caregivers who felt they had lost and/or were losing control over their life situation. Loss of control related to patients and family caregivers feeling heavily obligated to each other and their motivations to support one another was out of obligation versus a sense of personal responsibility which was not underpinned by obligation. Patients and family caregivers motivated by mere obligation to one another were generally more closed to one another emotionally, with their resistance to their roles causing them to only take part in supportive behaviours that were explicitly necessary. However, personal responsibility prompted patients and family caregivers to go above and beyond in terms of their explicit responsibilities to one another, partaking in voluntary, non-compulsory forms of care such as expressions of affection, reassurance, and appreciation. Further delineation between 'obliged' and 'personally responsible' patients and family caregivers in palliative care is needed to ascertain the limitations of mutual support between them when it is underpinned by mutual obligation.

Fourth, attention must also be given to how a sense of obligation or personal responsibility between the patient family caregiver in palliative care functions in

decision-making process pertaining to treatment and care. Decision-making, as the study has illustrated, was a multi-faceted process and was influenced by multiple factors including trust and closeness between the patient and family caregiver. Importantly, the study indicates that patients can involve family caregivers in decision-making as a form of reward for providing care and where the patient does not feel constrained in receiving care provided by the family caregiver. Moreover, family caregivers can have a desire to go above and beyond their fundamental caregiving responsibilities when motivated by personal responsibility to the patient. In the present study, family caregivers who were motivated by personal responsibility were more likely to be given an opportunity by the patient to contribute to the decision-making process pertaining to their care. Consequently, family caregivers who felt a deep sense of personal responsibility to their ill family member gained in some cases, a sense of control in the decision-making process in relation to the patient care. Obligated family caregivers on the other hand were not generally granted the same level of input in decision-making when compared to family caregivers who communicated a deep sense of personal responsibility to the patient. These findings indicate that while some family caregivers can resist over and above their core caregiving duties because of resentment over their loss of control in their own lives, a degree of control can be regained by building closeness, trust and relatedness with the patient and becoming part of the decision-making team with respect to the patient's treatment and care. The development of interventions focused on the needs of both patients and family caregivers in palliative care need to pay particular attention to family caregivers who feel heavily obliged to support their ill family member to fully ascertain how best to facilitate and/or include the family caregiver in decision-making about the patient's treatment and care.

Finally, research focused on relationship functioning between patients and family caregivers in palliative care should consider the process of concealment between patients and their family caregivers. The study's findings regarding concealment in palliative care are noted in relation to previous research on concealment within a palliative care setting (Lemus-Riscanevo et al., 2019, Martín-Fortea et al., 2020; Pinyopornpanish et al., 2017). While previous research has considered concealment as

maladaptive and as acts of self-preservation in the concealer (Martín-Forteza et al., 2020; Pinyopornpanish et al., 2017), the present study found the opposite to be case for some patients and family caregivers. Importantly, the study identified that an act of concealment could be a well-intentioned feature of a relationship in which the concealer attempted to protect or preserve their counterpart's emotional wellbeing. This finding has implications for future research because concealment is often interpreted as a negative attribute of the patient and family caregiver relationship, acting as an obstacle to open disclosure between the patient and family caregiver. This aspect of the study lends supplementary information to pre-existing frameworks, and in fact cast doubt upon the assumption that concealment, in particular, is a negatively influencing factor upon relationships in all cases. Concealment has been traditionally conceptualised as a behaviour motivated by self-interest, as stated by Merrell et al. (2024), for instance. The results of the present study indicate, however, that concealment is motivated in equal part for the preservation of self and for the preservation of the concealer's counterpart's wellbeing. The study found that concealment (albeit it be in some cases, temporary concealment) between the patient and family caregiver can also feature in the form of behaviours intended to be supportive by the patient and family caregiver. Further investigation into patient and family caregiver actions and behaviours in palliative care noted as concealing, particularly with respect to how they communicate and/or conceal their actual preferences for care, is needed.

8.2.2 Implications for policy

Within an Irish context, the needs of patients and family caregivers have been documented recently by the All-Ireland Institute of Hospice and Palliative Care's Report on the Department of Health's Public Consultation for the Palliative Care Policy for Adults (All- Ireland Institute of Hospice and Palliative Care, 2021), and are consistent with the reported concerns of patients and family caregivers in the present study. Findings from the afore-mentioned report included patient and family caregiver perceptions of insufficient training and education opportunities for family caregivers, and inadequate support for family caregivers, including the integration of formal 'sit

in' respite services. The above patient and family caregiver concerns are also emphasised in policy documents in other countries (Australian Department of Health, 2018; New Zealand Ministry of Health, 2001; Sleeman et al., 2021).

In recent years, Ireland has begun the move towards a public health approach for palliative care, the policies of which have begun to be implemented in practice. While several public health approaches have previously been proposed, including the World Health Organization (WHO) approach, health promotion approach and population-based approach (Dempers & Gott, 2017). The current approach has employed the commonalities of these three approaches (All Ireland Institute of Hospice and Palliative Care, 2017). Perhaps the primary aims of these policies are the combined mobilisation of community resources and the bolstering of health promotion and its applicability even at the end of life (Sallnow et al., 2016). The results of the present study illustrate clearly that family caregivers, while community resources themselves, could benefit significantly from the involvement of others to provide respite, counsel, or transport. These supports also act as health promoting behaviours as they are assistive in providing care directly to the patient or indirectly, by assisting the family caregiver in retaining the stamina and wellbeing required for palliative caregiving.

A recurrent feature of the data in the present study was the emphasis family caregivers placed on the flexibility and resilience they experienced when given the opportunity to have periods of respite. This finding is important as it suggests that family caregivers who are unable to access respite either through formal services or from other members of the family can experience caregiving burnout, and which in turn can have adverse impacts on the supportive relationship between patients and family caregivers. The capacity to perform caregiving duties outside of the core physical caregiving tasks (e.g., organising appointments with healthcare providers and overseeing correct use of medications for patients in the home setting) was in some cases lessened by the emotional fatigue experienced by the family caregiver. However, family caregivers who were given opportunities for respite from caregiving duties appeared to be somewhat more content in their caregiving role when compared to those who felt they had little opportunity to temporarily relieve themselves from their caregiving role. In addition, family caregivers who felt their respite was sufficient

tended to express greater confidence in and satisfaction with their caregiving role (when compared to those who did not feel they had sufficient respite) because they were reassured by the fact that others could assist them when they (the family caregiver) needed reprieve from caregiving. These findings are particularly important because we know that perceived support has a greater impact upon family caregivers' perceived degree of burden than received support (Del-Pino-Casado et al., 2018). As such, a key implication for policy is the need and willingness of other family members to support the patient and primary family caregiver. Moreover, a better understanding of the composition of the support structures around the patient and family caregiver is needed to improve healthcare professionals' abilities to assess the relevance of respite from caregiving for patients and family caregivers, as perceived by both patients and family caregivers. Of note, the study identified that not only does respite from caregiving enable and support the family caregiver in palliative care, the availability of respite to the family caregiver can also foster support between the patient and family caregiver because patients in the study also encouraged their family caregiver to avail of respite to lessen carer burden.

The study identified a number of ways in which other members of the family were influential on the degree to which patients and family caregivers were able and comfortable to spend time apart, seek psychological support from others, and have the time and capacity to provide emotional support to one another. The all-consuming nature of the patient and family caregiver relationship required periods of respite to alleviate distress and strain in both patients and family caregivers. Patient and family caregiver perceived distress and their perceived lack of respite to support them both heightened their feelings of and in some cases, 'burden' of obligation to each other. However, support from the wider family allowed patients and family caregivers to feel more secure in their roles, with the knowledge that if they were unable to provide emotional support to one another, other family members could intervene before significant strain developed between the patient and family caregiver. While the findings of the present study contribute to the development of dyadic-centric models of care, they also warrant further policy review in relation to the effects of the wider family on the patient and family caregiver relationship, particularly with respect to

how the patient and family caregiver are given respite from one another. The findings have implications for policy as it highlights the importance of the dual role of the family caregiver not only as an informal care provider, but also as a part of the unit of care itself. The findings support the need for patients and family caregivers who do not have a supportive wider family network to receive respite through formal means because the study has identified that respite whether it be from family or formal services, fosters supportive relationships between patients and family caregivers.

The All-Ireland Institute of Hospice and Palliative Care's Report on the Department of Health's Public Consultation for the Palliative Care Policy for Adults (All-Ireland Institute of Hospice and Palliative Care, 2021) also documents the need for family caregivers to empower themselves to be knowledgeable about the patient's needs and to be effective advocates for their ill family member. In the context of the findings from the present study, the realisation of the above indicates that healthcare professionals have a vital role in providing education, training, and support to family caregivers who are eager to gain the knowledge and skills needed to provide optimal care to the patient. Importantly, the study identified that family caregivers who had access to knowledge and training from healthcare services felt they were relatively secure in their roles and that their ill family member trusted them in the context of their expertise and confidence that they (i.e., the family caregiver) gained from healthcare professionals. Family caregivers who reported a high propensity to actively engage with healthcare professionals felt that formal education and advice from healthcare professionals enabled mutual support between them and the patient because patients reciprocated in the provision of support by expressing appreciation of the family caregiver's effort to be competent in a caregiving role. Hence, from a policy perspective, the findings point to the importance that healthcare professionals' continued education and support of the family caregiver has for both the patient and family caregiver in the context of both fostering supportive behaviours between the patient and family caregiver and the family caregiver potentially becoming more able in a caregiving role.

Lastly from a policy perspective, the study draws careful attention to the family caregiver role in shared decision-making, a process that involves not only the

healthcare professional and patient but also the family caregiver. The study found that the efficacy of family caregivers in decision-making was dependent on the degree to which the family caregiver and patient felt constrained in relation to one another. The author identified that when both patients and family caregivers felt constrained in their respective roles of care recipient and care provider, patients were less likely to actively involve their family caregivers in discussions with healthcare professionals that were explicitly focused on decision-making. However, when patients felt less constrained despite their reliance on their family caregiver, patients and family caregivers were more collective in the decision-making process for care. Moreover, the family caregiver involvement in decision-making when actively encouraged by the patient resulted in some patients placing more value on their caregiver preference or judgement than their own which has implications for safeguarding patient autonomy when making decisions about care (Billings & Krakauer, 2011; Lolich & Lynch, 2017). From a policy perspective, increased attention to the nuances of shared decision-making in palliative care in the context of both patients' and family caregivers' perceived control in the decision-making process and which appear to be heavily contoured by both the patient and family caregiver feeling constrained in relation to one another, is warranted.

8.2.3 Implications for practice

The findings of the study have implications for clinical care and practice, particularly with a view to interventions focused on fostering mutually supportive relationships between patients and family caregivers. It is expected that the findings of the study will be of benefit to health and social care professionals who work to facilitate patient autonomy in decision-making whilst also supporting the needs of family caregivers as they strive to adapt to the challenges of supporting and caring for a person with life-limiting illness. A key implication of the study's findings for practice is the complexity in how patients and family caregivers in palliative care can be mutually supportive. The author identified that there are multiple dimensions to patient and family caregiver mutual support in palliative care (chapter four), that a range of factors can facilitate or restrict supportive relationships between patients and family caregivers (chapter five),

and that some behaviours intended to be supportive may undermine relations between patients and family caregivers, and which in turn impact on how both the patient and family caregiver engage with healthcare professionals in decision-making for treatment and care (chapter six). Hence, the findings point to why healthcare professionals should not attempt to apply a one size fits all approach in their interactions with the patient and family caregiver, including when they engage directly with patients and family caregivers in conversations around decision-making and advise the patient and family caregiver in relation to care.

That said, specific patterns and processes do explain the how and why of supportive relationships between patients and family caregivers. For instance, in cases where patients felt obliged to receive care from the family caregiver, they restricted family caregiver input in decision-making. Such disempowerment of the family caregiver caused in some cases, resentment and conflict between the patient and family caregiver. Patients and family caregivers who felt they had little choice but to give and receive support tended to point to mutual conflict and seemed conflicted in their support of one another. Patient and family caregiver mutual conflict was in of itself a key context which explained why some patients resisted family caregiver involvement in decision-making about their care. However, conflict featured much less among patients and family caregivers when patients and family caregivers were trusting of one another and when they actively sought to alleviate distress for one another. Of key importance is the fact that both patients and family caregivers managed to cope with, resolve or accept their differences when both felt they were personally responsible for their respective other, a level of personal responsibility that extended beyond merely feeling obligated to support one another. Importantly, where personal responsibility was mutual between patients and family caregivers, patients and family caregivers felt secure by having a shared perspective. The above evidence is particularly important for healthcare professionals in the field who seek to promote patient and family caregiver understanding of each other's perspective and facilitate patient and family caregiver awareness of each other's needs. Moreover, the above findings are particularly valuable for practice in the context of the limited time and resources healthcare professionals may have to help patients and family caregivers

understand their choices in relation to each other and within the possibilities and constraints of their situation.

Patients and family caregivers in the study who were highly emotionally communicative with and supportive of one another were knowledgeable about the wishes of their counterpart, both in terms of what type of support they required in general and in relation to their preferences and wishes for care. This finding has implications for practice because patients and family caregivers who reciprocate in providing emotional support to one another and who communicate openly with one another may feel as a result more secure when confronted with conversations and/or making decisions about care, including end-of-life care. In addition, family caregivers who are fully in tune with the wishes and preferences of the patient may be better equipped to act in accordance with the patient's expressed wishes for care in the event of the family caregiver having to become a decision-maker by proxy for the patient. While proxy decision-making has been a highly investigated topic for patients with dementia and their family caregivers (e.g., Huang et al., 2020), guidelines for facilitating proxy decision-making in palliative care require extensive review in practice (Spalding, 2021). It is important that family caregivers be supported to develop their knowledge and understanding of the decision-making patterns of the family member they care for. Healthcare professionals in the field also need to be appropriately equipped to support the family caregiver to accomplish the above. Supporting the family caregiver in situations where the patient is unable to make a decision may necessitate further training for healthcare professionals.

From a practice perspective, the study indicates that family caregiver respite and indeed the respite that patients experience when family caregivers spend time apart from them, can help sustain the patient and family caregiver relationship and their mutual resilience. Traditionally, research has investigated the benefits of respite for family caregivers as opposed to patient (Payne et al., 2004). However, the present study found that respite for the family caregiver could also be beneficial for patients because not only did it enable the family caregiver to sustain their caregiving role, respite for family caregivers also made patients feel that they could reciprocate in support through alleviating the family caregiver burden that might otherwise have

increased without respite for the family caregiver. It must be noted that majority of patients and family caregivers in the study reported low levels of support from the wider family in terms of taking over caregiving duties from the family caregiver when the family caregiver felt increasingly distressed in their caregiving role. The study highlights how *family* (in the case of the present study, absence of support from the wider family) can be a primary stressor rather than stress alleviator for the patient and family caregiver in palliative care (Benson et al., 2023). In the absence of support from the wider family, family caregivers did not have the opportunity to discuss with other members of the family elements of the family caregiving experience which they felt were too distressing or burdensome to discuss with the patients themselves. Limited support from the wider family invariably made family caregivers prioritise the patient above their own needs, leading to burnout and in some cases, resentment towards both the patient and the wider family. Hence, healthcare professionals in palliative care need to be attuned to the importance of implementing a respite care plan for patients and family caregivers when support from the wider family is not forthcoming. Social support networks must be aware of the benefits of patient respite from family caregivers in addition to the benefits gleaned by family caregivers who receive respite. Indeed, the benefits that dyads receive from mutual respite appear to outweigh the sum of their parts, with the present study revealing that patients and family caregivers that are both given the opportunity to spend time out of the home without one another return to the caregiving setting with increased patience, stamina and affection for one another. The prevention of burnout for both patients and family caregivers in palliative care is needed not only so that patients and family caregivers remain able to provide support to one another but also to ensure that they maintain capacity to receive support from one another.

Findings relating to limits on autonomy and exacerbation of feelings of constraint dependent on community mobilisation particularly are mirrored by the current public health approach to palliative care. While this approach has not considered mutual support, as it is a novel concept, acknowledgement has been given to the need for family caregivers and patients to have respite for and from one another in order to function well as a dyad (Sallnow et al., 2016). The dyad-centric model of care is central

to this new approach, with Sallnow et al (2016) highlighting that patients are more likely to achieve their preferred place of death when the dyad, the patient and family caregiver, are supported by the wider community, rather than focusing support on the patient alone. We know that dyadic models of care result in dyads experiencing similar perceptions of support, stress and sense of security (Liljeroos et al., 2021), due in part to their likelihood to create a shared view of their circumstances (Ando et al., 2019). The present study has confirmed these findings, by illustrating the benefits of social supports that benefit both patient and family caregiver, and the freedoms it allows the unit when both patient and caregiver are given respite and care. Thus, the learning for practice is that the dyad is an emotionally related, symbiotic unit which requires a dyad-centric model of care directed at the unit rather than an individual, by both formal, palliative care services, and informal community resources.

8.3 Conclusion

The study has evidenced the existence and processes of mutual support between patients and family caregivers in palliative care. Identification of key processes of mutual support and the contexts which underpin them is the first step towards formulating strategies to help patients and family caregivers support one another, but also in deciphering how to develop interventions which can build mutual support between patients and family caregivers. Overall, the findings of the study provide the basis for a much-needed focus on the potential make up and benefits of patient-caregiver dyadic interventions in palliative care particularly where such interventions include focus on facilitating mutual disclosure and open communication in the decision-making process for treatment and care. Mutual support between patients and family caregivers in palliative care can help both the patient and family caregivers feel a sense of control over their circumstances, something that we know often diminishes for both patients and family caregivers as patients advance in their illness. Control and autonomy are important for both patients and family caregivers in palliative care (Foley et al., 2014; Munck et al., 2008). Healthcare professionals need to balance between helping family caregivers feel a sense of control whilst they protect patient autonomy in decision-making for patient treatment and care. Importantly, the

study has shown that when both the patient and family caregiver feel able to voice their concerns and preferences for care to one another, they feel supported by one another. It is possible that helping both the patient and family caregiver feel in control may help to reduce conflict between patients and family caregivers and foster supportive relations between the patient and family caregiver.

However, educating all members of the healthcare team about patient and family caregiver mutual loss including instruction on how to source additional support to help the patient and family caregiver adapt to their loss remains key. This is because a central observation from the study is that feelings of loss predominated for both patients and family caregivers regardless of the quality of the relationship they reported or of how in control or not in control they felt in their roles and/or over their circumstances. This thesis forms the nucleus of potential future interventions aimed at patient and family caregiver units and their wider social support networks. Overall, the findings warrant addressing the consequences of mutual loss for patients and family caregivers by focusing on relationship change between patients and family caregivers and on how patients and family caregivers adapt to their own and each other's loss.

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Appendices

Appendix A: Published Works from the Study

(i) Mutual support between patients and family caregivers in palliative care: A systematic review and narrative synthesis (McCauley et al., 2021)



Review Article



Mutual support between patients and family caregivers in palliative care: A systematic review and narrative synthesis

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Abstract

Background: Patients in palliative care are usually conceptualised as recipients of support from family caregivers. Family caregivers in palliative care are typically defined as providers of support to patients. Little is known about reciprocal dimensions of support provision between patients and family caregivers in palliative care.

Aim: To identify processes of mutual support between patients and family caregivers in palliative care and factors that contribute to or obstruct mutual support between patients and family caregivers in palliative care.

Design: Systematic review and narrative synthesis of original peer-reviewed research published between January 2000 and March 2020.

Data sources: Medline, CINAHL, Embase, AMED, PsycINFO and PsycARTICLES.

Results: After full-text screening, 10 studies were included. We identified that patients and family caregivers in palliative care can support one another by mutually acknowledging the challenges they face, by remaining positive for one another and by jointly adapting to their changing roles. However, patients and family caregivers may not routinely communicate their distress to each other or reciprocate in distress disclosure. A lack of mutual disclosure pertaining to distress can result in conflict between patients and family caregivers.

Conclusions: Few studies have focused in whole or in part, on reciprocal dimensions of support provision between patients with advancing non-curable conditions, and their family caregivers in palliative care. Further research is required to identify key domains of mutual support between patients and family caregivers in palliative care.

Keywords

Systematic review, caregivers, patients, palliative care, mutual support

What is already known about the topic?

- Family caregivers are a primary source of support to patients in palliative care.
- Provision of support between the patient and family caregiver in palliative care is often assumed to be unidirectional – from family caregiver to patient.
- Little is known about reciprocal dimensions of support provision between patients and family caregivers in palliative care.

What this paper adds?

- Mutual support between patients and family caregivers in palliative care can be underpinned by mutual recognition of each other's needs and by remaining positive for one another.
- Patient and family caregiver failure to disclose their distress to each other can result in conflict between the patient and family caregiver and limit mutual support between the patient and family caregiver.
- Support from the wider family can allow for greater emotional engagement between patients and family caregivers in palliative care.

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Implications for practice, theory or policy

- Reconceptualising the patient in palliative care as having capacity to provide support to family caregivers is needed to advance our understanding on this topic.
- Supporting patients and family caregivers in palliative care to disclose their distress to each other has potential to alleviate concerns for both patients and family caregivers and promote concordance among patients and family caregivers in the decision-making process.

Introduction

The palliative care trajectory can be accompanied by a period of considerable distress for patients.¹ Distress can be physical, psychological, and existential in nature, comprising of fatigue, pain, sadness and worry.¹ Between 30% and 40% of patients in palliative care experience acute levels of psychological morbidity.² Patients in palliative care rely heavily on assistance from informal sources of support such as family.³ The term family in palliative care includes not only formalised relationships, but also those that are self-defined or patient-defined as significant. Family caregivers in palliative care are family members, friends and or other people who have emotional and social bonds with a patient, who undertake significant nonprofessional or unpaid care for patients.⁴ They provide a combination of physical, psychological, social and existential support to their family member.⁵ They also experience high levels of physical, emotional and psychological burden, in their case, associated with their caregiving role.⁶ In some cases, family caregivers in palliative care can also feel ill-equipped in their caregiving role⁷ and patient overestimation of caregivers' self-efficacy can result in anxiety and dissatisfaction among family caregivers.⁷

Caregiving by family caregivers comprises a significant component of caregiving in palliative care.⁸ As the delivery of palliative care services moves increasingly to community and/or primary care,⁹ there is a growing expectation that family caregivers will become even more involved in the delivery of palliative care.¹⁰ Moreover, fiscal constraints in formal care provision means that patients in palliative care may become increasingly dependent on family caregivers.¹¹ Family caregivers in palliative care are by context key stakeholders in the decision-making process^{12,13} and they operate as an extension to formal services.¹⁴

Notwithstanding the central role of family caregivers in palliative care in caring for their family member, there has been less focus on how patients function as providers of support to their caregiver or how both support one another in palliative care.¹⁵ Studies in palliative care have reported on caring roles enacted by patients towards family caregivers. For example, patients have been shown to prioritise their family caregiver's wellbeing and attempt to reduce the burden they place on

them.¹⁶ Patients have also concealed their own needs from their family caregiver and encouraged family caregivers to take respite during their caregiving role to alleviate their family caregiver distress.¹⁷

However, the *mutual* nature of support provision between patients and family caregivers in palliative care is not well understood. We know that the burden that patients in palliative care feel that they impose on their family caregivers and the duty that family caregivers feel towards the person they care for can make both prioritise each other's needs over their own.¹⁸ Indeed, studies in palliative care have shown how remaining positive for one another can help both patients and family caregivers adjust to advanced illness¹⁹ and how remaining collectively steadfast in the face of illness is a dimension to caring.²⁰ However, reciprocal dimensions to support provision between patients and family caregivers are not routinely mapped out.¹⁵ A systematic review of mutual support between patients and family caregivers in palliative care is therefore useful to enhance our understanding of patients' and family caregivers' negotiation of the palliative care journey as a unit.

Aims

The purpose of this review was to systematically identify and examine original evidence on mutual support between patients and their family caregivers in palliative care. The review aimed to identify processes of mutual support between patients and family caregivers in palliative care and describe factors that can contribute to or obstruct mutual support between patients and family caregivers in palliative care.

Methods

We undertook a systematic review and narrative synthesis of original peer-reviewed studies published in full and in English between January 2000 and the end of March 2020, pertaining to mutual support between family caregivers and patients in palliative care. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart²¹ to map out the number of records identified, included and excluded, and the reasons for exclusion. The review was carried out between January 2020 and March 2020.

Search strategy

The search was conducted using the following databases: Medline; CINAHL; Embase; AMED; PsycINFO and PsycARTICLES. Search term pathways used in electronic searches were as follows: Palliative care/terminal care/hospice care/end of life care/palliative approach/advanced illness/serious illness/progressive illness 'AND' family carer*/family caregiver*/primary caregiver*/primary carer*/patient*/family* 'AND' psychosocial support/social support/mutual support/support exchange/reciprocal support/reciprocity. The asterisk in this case was used in order to capture the plural case of these terms. The above search terms were chosen in order to capture studies comprising patients and/or family caregivers in palliative care living with advancing non-curable illness. With respect to mutual support, we chose specific search terms that would capture reciprocity and exchange of support between patients and their family caregivers.

Inclusion/exclusion criteria

We included original empirical peer-reviewed studies that reported on mutual support and/or reciprocity between patients and family caregivers where it was evident that patients and/or family caregivers had received or were receiving palliative care. Given the aims of our review, appraisal pertaining to validity and reliability standard in systematic reviews of interventions was not appropriate. Our protocol was not to exclude on the basis of evidence level because studies to answer our review questions were as to be expected empirical studies which ranged in evidence level (e.g. cohort studies, qualitative studies). For the purpose of this review, we defined palliative care as treatment which aims to meet the physical, social and emotional needs of patients with clearly advancing, non-curable conditions and their caregivers. We did not limit the review to specialist palliative care or to end-of-life care. We included not only studies which sampled both patients and the family caregivers, but also studies that sampled only patients or only family caregivers once the data generated pertained to mutual support or reciprocity between patients and family caregivers. We excluded literature that was not original peer-reviewed published studies (i.e. grey literature) and studies not published in full and in English.

Extraction

The first author (RMcC) ran the search and completed a first screen of all titles and abstracts. Both RMcC and the last author (GF) then independently screened each title and abstract based on the inclusion/exclusion criteria. For articles that were deemed to possibly meet the inclusion criteria, full texts of these articles were retrieved by RMcC

and read independently by RMcC and GF. Any disagreements regarding inclusion at this point were resolved through discussion and further review of the article. Figure 1 outlines the PRISMA flow diagram of the conducted review. We tabulated the included studies into a Table 1 under the standard domains of authors, sample, location, methods, study aims and a summary of key findings.

Quality assessment

The quality of each selected study was assessed by using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers³² tool. This tool allows for a systematic and replicable method of assessing the quality of studies from a variety of methodological designs. Studies are given a quality assessment score based on a 14-item checklist for quantitative studies and a 10-item checklist for qualitative studies. Quality rating scores range between 0 and 1.0 for each study. We used this tool because it allowed us to compare quality across selected studies. The quality of each included study was independently assessed by RMcC and GF and where scores differed, the central value was taken. The quality of studies³² ranged from adequate to strong. Table 1 includes the quality metric for each included study.

Synthesis

We conducted a narrative synthesis of the selected studies.^{33,34} A narrative synthesis is commonly used to synthesise evidence from studies that are heterogeneous in design and does not necessarily intend to transform data beyond the findings of the primary studies.³³ It adopts a textual approach to the process of synthesis to tell the story of findings from the included studies.³⁴ First, we looked exhaustively at the evidence in each study that captured and/or shaped processes of mutual support between patients and family caregivers, including factors that enabled or restricted mutual support between patients and family caregivers. We then collated and summarised the evidence from each study.³⁴ Next, we explored relationships in the data, by comparing the data both within and across the studies.³⁴ Looking iteratively for similarities and differences in the data both within and across studies helped us identify the evidence that more fully encapsulated key processes of mutual support and the factors that impacted on it. We then grouped findings into categories³⁴ which we felt best described key processes of mutual support and/or key factors that shaped mutual support. Both the grouping of findings into categories and the labelling of the categories were decided upon by mutual agreement between authors.

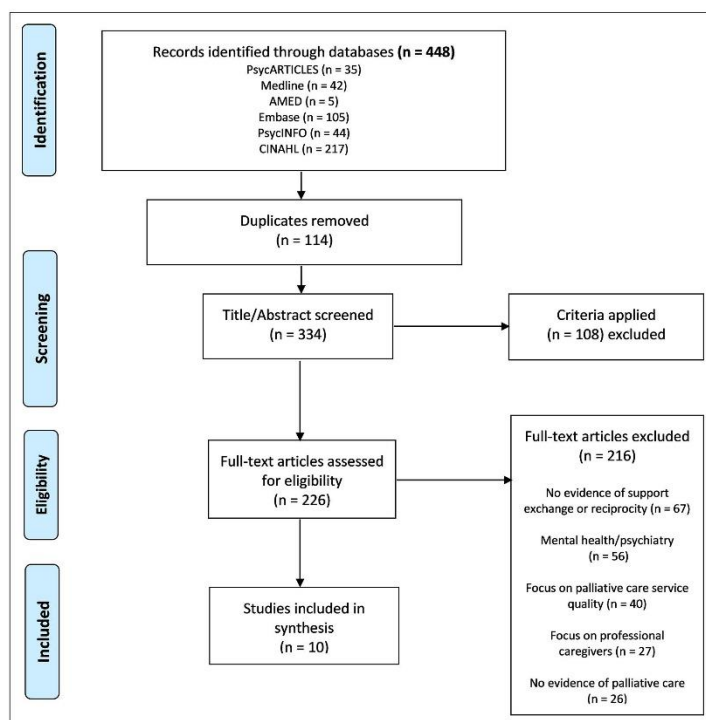


Figure 1. PRISMA flow diagram.

Findings

Ten studies^{22–31} met the inclusion criteria and were included in the synthesis. The studies extracted varied in scope, design and in their aims (see Table 1). Of the studies included, seven were qualitative^{22,24,25,27–29,31} and three were quantitative^{23,26,30} (including one randomised-controlled trial,³⁰ one longitudinal-cohort study²³ and a cross-sectional cohort study²⁶). The studies were conducted in the UK,^{22,29} Canada,²⁶ Denmark,³⁰ Sweden,²⁷ Colombia,²⁸ and the United States.^{23–25,31} All studies sampled participants through healthcare settings including a hospital oncology department,³⁰ a neurology outpatient clinic,²² an oncology outpatient clinic,²⁶ specialist cancer

centres,^{24,25,29} a hospital palliative care unit²⁸ and a hospice.³¹ Family caregiver participants were caregivers of cancer patients only in all studies except one³¹ which included caregivers of both cancer and non-cancer patients. None of the studies found reported exclusively on mutual support between patients and family caregivers in palliative care and only one study²⁵ aimed from the outset to investigate processes of support and care between patients and family caregivers. Across 9 of the 10 studies that included carer participants in the sample, family caregivers were reported as spouses,^{24–26} partners of a couple,²³ a mixture of family members and friends,^{28,29} a mixture of partners (of a couple) and adult children^{27,30} and as non-familial related caregivers.³¹

Table 1. Summary of studies.

Study	Participants	Location	Methods	Study aims	Findings on the topic	Quality
Ando et al. ²²	<i>n</i> = 26 (26 ALS patients)	Hospital outpatient neurology clinic: Liverpool, UK	Qualitative: thematic analysis; semi-structured interviews	To explore ALS patients' concerns that relate to quality of life for people with ALS	Significant others provided physical care to patients and supported them emotionally in their illness. Patients sought to minimise the impact of limitations and burden associated with ALS on significant others.	0.725
Badr et al. ²³	<i>n</i> = 482 (191 female metastatic breast cancer patients, 191 male partners)	Medical setting not stated; specific location not stated, USA	Quantitative: prospective longitudinal; stress, dyadic adjustment and coping self-report measures	To evaluate whether common dyadic coping was associated with less cancer-related distress and greater dyadic adjustment for female metastatic breast cancer patients and their male partners	Patients discussed their distress with partners more often than partners discussed their distress with patients. Common positive dyadic coping resulted in better dyadic adjustment for the dyad. Negative dyadic coping resulted in an increase in distress for both patients and family caregivers and a decrease in dyadic adjustment for patients and their family caregivers.	0.875
Badr and Taylor ²⁴	<i>n</i> = 25 (13 lung cancer patients (<i>n</i> = 12 metastatic/advanced cancer), 12 spouses)	Cancer centre: Texas, USA	Qualitative: grounded theory; semi-structured interviews	To examine the effect of lung cancer on the spousal relationship	Dyads experienced a wide variety of social constraints including denial, avoidance and conflict that hindered open spousal communication. Despite these constraints, participants who talked openly with each other about their relationships reported fewer constraints and better communication about cancer.	0.825
Gardner ²⁵	<i>n</i> = 70 (35 advanced cancer patients, 35 spouse caregivers)	Cancer centre: specific location not stated, USA	Qualitative: grounded theory; semi-structured interviews	To investigate processes of care, support, communication and search for meaning between older adults living with advanced and terminal cancer, and their caregivers	Concerns about treatment and illness trajectory were common for both patients and family caregivers but were not always addressed by the dyad. Couples supported each other by expressing hopefulness, acknowledging likelihood of loss and constructing a shared view of their circumstances.	0.825
Lo et al. ²⁶	<i>n</i> = 556 (278 metastatic/advanced cancer patients, 278 spouse caregivers)	Oncology outpatient clinics: Toronto, Canada	Quantitative: cross-sectional cohort study; structural equation modelling; psychological self-report measures relating to distress, burden and social relatedness.	To test a heuristic model which examines the emotional states of cancer patients and their caregivers in an interdependent relational system	Non-disclosure of negative feelings resulted in maladaptive communication and coping for both patient and caregiver. Family caregivers were more distressed by patients' distress than patients were distressed by caregivers' distress.	0.825

(Continued)

Table 1. (Continued)

Study	Participants	Location	Methods	Study aims	Findings on the topic	Quality
Person and Sundin ²⁷	n = 12 (12 family caregivers of advanced lung cancer patients) (mix of spouses (of a couple) and adult children)	Medical setting not stated; Stockholm, Sweden	Qualitative: phenomenology; semi-structured interviews	To explore the meaning of family caregivers' lived experiences of their months as a family member had been diagnosed with inoperable lung cancer	Caring for a family member with advanced cancer resulted in feelings for family caregivers of increased stress to patients, increased stress to family caregivers, and negative beliefs about patients' family caregivers. Family caregivers suggested that their relationship with their ill family member was no longer reciprocal because of the responsibilities assumed by them as family caregivers.	0.65
Rocio et al. ²⁸	n = 24 (12 advanced cancer patients, 12 family caregivers) (family caregivers - mixture of family members and friends)	Palliative care unit at a national cancer institute; Bogota, Columbia	Qualitative: phenomenology; semi-structured interviews	To explore the patient/family caregiver experience during the transition from hospital palliative care to home	Family caregivers supported patients by providing physical and emotional care to them. The bond between patient and family caregiver became strong and insular as both managed their shared crisis. Family caregivers had concerns about coping as patients became more dependent on them.	0.625
Stamataki et al. ²⁹	n = 53 (53 family caregivers of cancer patients) (mixture of family members and friends)	Cancer centre; Manchester, UK	Qualitative: longitudinal; semi-structured interviews	To investigate the experience of family caregivers of patients with cancer across four timepoints in a 12-month period including palliative care	Family caregivers reported that mutual recognition and sharing of the cancer experience strengthened the patient-caregiver relationship. How well family caregivers felt they were coping depended on how well they felt their partner was coping. Conflict between patients and family caregivers also arose as a result of patient irritability and behaviour change.	0.80
Von Heymann-Huam et al. ³⁰	n = 598 (340 cancer patients, 258 family caregivers) (family caregivers: mixture of spouses (of a couple) and adult children)	Hospital oncology department; Copenhagen, Denmark	Quantitative: randomised controlled trial; anxiety, depression and coping self-report measures	To investigate whether a specialised palliative care and dyadic psychological intervention increased aspects of dyadic coping in patients with cancer and whether aspects of dyadic coping mediated significant intervention effects on caregivers' anxiety and depression	The intervention significantly increased dyadic coping (e.g. shared problem solving) in patients and caregivers, and stress communication by partner caregivers. Common aspects of dyadic coping, and stress communication did not mediate significant intervention effects on caregivers' anxiety and depression.	0.875
Wittenberg-Lyles et al. ³¹	n = 30 (30 non-familial related caregivers of palliative care patients)	Urban hospice program; specific location not stated; Western USA	Qualitative: a priori coding; semi-structured interviews	To explore the transactional nature of reciprocal suffering by examining caregivers' concerns	Family caregivers reciprocated in feelings of distress when caring for patients. Caregivers placed more emphasis on patients' physical wellbeing than on their own physical wellbeing.	0.75

Constructing a shared view

A common way in which patients and family caregivers supported one another was through mutual acknowledgement and understanding of the challenges they both faced.^{22,24,25,28,31} Shared acknowledgement and understanding was important when patients and family caregivers received new information about the patient's trajectory and/or when the patient's physical condition had changed.³¹ Indeed, mutual understanding of the situation at hand enabled patients and family caregivers to communally appraise treatment options and make decisions about care in a timely manner.^{24,28} Consensus among patients and family caregivers in the decision-making process was a feature of positive dyadic coping between patients and family caregivers.^{23,29,30} However, consensus also featured (inversely) in the context of mutual avoidance.^{23,30}

Shared positivity

Mutual acknowledgement and understanding was in most cases underpinned by patients' and family caregivers' efforts to foster optimism for each other.^{23–25,30} Shared positivity was perceived as being mutually beneficial because it enabled both patients and family caregivers to maintain hope for the future.²⁵ Remaining positive for each other was also framed by acknowledgement of past positive experiences they had shared and were grateful for.²⁵ Indeed, remaining positive as a unit assisted patients and caregivers to adjust to changing circumstances^{24,25} and adjusting well together was in some cases, a latent dimension to how patients and family caregivers supported each other.^{23,25,29}

Shared positivity was a feature of positive dyadic coping and was generally associated with both better dyadic adjustment and less illness related distress for both patients and family caregivers.²³ However, due to the perceived importance patients place on a shared positive outlook, caregivers sometimes felt it necessary to remain visibly optimistic for patients even in the face of significant concerns.²⁵ In addition, caregivers' compartmentalisation of negative emotions and their positive emotional support of the patient could result in emotional burnout in caregivers.³¹

Importantly, the wider family encouragement of patient and family caregiver shared positivity helped patients and family caregivers sustain their positive support and encouragement of one another.^{26,28} Increased support from members of the wider family alleviated caregiver distress and the degree to which patients perceived themselves a burden on the family caregiver.^{26,28} The presence of other family member support allowed for greater emotional engagement between patients and their family caregivers.²⁶ By contrast, in situations where support from the wider family was reported as absent, family caregivers

reported feeling alone and difficulty in remaining positive for the patient.³¹

Shared distress

Both patients and family caregivers reported distress during the course of illness.^{22,24–26,29–31} Family caregivers' observation of the patient in physical and emotional distress caused significant emotional distress for family caregivers.²⁷ Emotional distress encountered by family caregivers had the capacity to escalate patients' emotional distress^{22,24,30} and stressful situations encountered by both patients and family caregivers was perceived to increase distress for each other.³⁰ Overall, patients and family caregivers were interdependent for perceived emotional distress.

Escalation of distress for patients and family caregivers was associated with common negative dyadic coping^{29,30} and poor adjustment to different and/or new roles.^{24,25,30,31} For example, distress for both patients and family caregivers arose from their concerns about financial matters or change in roles, with some family caregivers having to cease or limit their professional roles because of caregiving duties, with some being forced to prepare for the financial burden arising from providing care and anticipated funeral expenses.^{22,24,29} Perceived distress about the future was also shared because of mutual concern about how each other would cope with further deterioration in the patient's health.²² Of note, shared distress in the absence of close relatedness resulted in an escalation of negative feelings towards each other.³⁰

Some patients and family caregivers sought to conceal their concerns for the benefit of each other.^{22,24,25} Non-disclosure by family caregivers was perceived effective by family caregivers to help the patient maintain a positive outlook for the future.²⁵ However, reluctance to disclose feelings of distress to one another could result in both patients and family caregivers internalising their distress.^{24,29} Internalisation of distress by patients and family caregivers could then undermine mutual support and increase tension between patients and family caregivers.²⁴ In some cases, patients reported frustration and an increase in conflict between them and their family caregiver if patients perceived that their family caregiver avoided communicating their distress to them or did not reciprocate in disclosure of distress.²⁴

Negotiating new roles

Both patients and family caregivers acknowledged the challenge of adapting to their new and/or altered roles – as a care recipient or caregiver.^{24,25,29,31} Adjusting to the responsibility for the care and pain management of the patient was particularly challenging for some family caregivers^{27,28} and they struggled when their efforts did not

alleviate the patient's suffering.²⁹ For both patients and family caregivers, the process of adapting to new roles included accepting the need to relinquish previously held professional roles^{24,29} and negotiate the conflict arising from changing roles with their partner.^{25,31} Both patients and family caregivers reported change in the balance of power and control between them.^{24,25,30,31} Perceived change in balance of power was associated with role reversal, for example, in cases where those who were previously dependent on the other became the caregiver.^{24,25,30} However, reciprocal support between patients and family caregivers was also expressed even when patients and caregivers had exchanged dependent roles.³¹

Some family caregivers indicated that adapting to their new role as a family caregiver was hindered by a lack of social relatedness²⁶ or support from the wider family.³¹ Insufficient support from other members of the family as perceived by family caregivers, frustrated family caregivers particularly in situations where support from the wider family was perceived as tokenistic by the family caregiver and was limited primarily to when death of the patient was imminent.³¹ Feeling unsupported by other family members made family caregivers feel isolated and/or lacking in self-efficacy in their role as a family caregiver.^{27,29,31}

Discrepancy in mutual support

Discrepancies existed among patients and family caregivers in terms of supporting one another. Family caregivers were less likely to communicate their distress to patients compared to how often patients communicated their distress to them.²³ Some patients rated their family caregivers more positively than the family caregivers rated them (the patient) in terms of ability to give support.²³ Some family caregivers viewed their needs as secondary to those of their family member whom they cared for²⁴ and sacrificed their own interests in the process of caring.^{22,27} Family caregivers strove to conceal their concerns from patients to remain 'strong' for patients²⁹ even though they revealed their concerns to healthcare professionals and other members of the family.^{24,25} Patients also valued their family caregiver's wellbeing over their own and they concealed their physical symptoms in their effort to alleviate family caregiver burden.²²

Patients' and family caregivers' ability to support one another was also shaped by how patients and family caregivers reciprocated or did not reciprocate in their spiritual support of one another.^{25,31} A shared emphasis on spirituality was a dimension to enabling patients and family caregivers to support one another.³¹ Conversely, differences or conflict between patients and family caregivers on the relevance of spirituality meant that offers of spiritual support by one to the other were judged ineffective.²⁵

Discussion

This review aimed to identify processes of mutual support between patients and family caregivers in palliative care and to describe factors that can contribute to or obstruct mutual support between patients and family caregivers in palliative care. As stated, none of the studies found reported solely on mutual support between patients and family caregivers and only one study²⁵ had aimed to explore processes of mutual support between patients and family caregivers. Nearly all studies were conducted in developed western countries which could affect verbal expressions of mutuality and expression of support, or indeed propensity to engage in research focused on relationships and family support. Overall, the literature reviewed suggests that patients and family caregivers can support one another by mutually acknowledging the challenges they face, by fostering optimism for one another, and by negotiating together the change in their roles. However, in order to minimise causing distress for each other, patients and family caregivers may not routinely communicate their distress to each other or reciprocate in disclosure of distress. A lack of mutual disclosure can result in conflict between patients and family caregivers. Distress for both patients and family caregivers can arise in part, from the challenges associated with changing roles. Family caregiver distress can escalate if they feel unsupported by other members of the family.

Findings identified in this review resonate with the wider literature, including literature beyond palliative care. A study on distress and quality of life in patient and caregiver dyads facing stem cell transplant in cancer,³⁵ also found distress among caregivers and patients to be interdependent and that patients' physical wellbeing accounted significantly for caregiver wellbeing. Correlation of symptoms between stroke survivors and their family caregivers has also shown that family caregivers experience increased emotional distress caring for their family member when they perceive their family member becoming more severely affected by their illness.³⁶ In stroke survivorship, family caregiver optimism also has capacity to alleviate patient distress.³⁷

The importance of mutual understanding between patients and family caregivers has been reported elsewhere (e.g. inflammatory arthritis, multiple sclerosis), where jointly negotiating the effects of illness was also a prerequisite for dealing with the impact of the condition on both patients and family caregivers.^{38,39} Findings pertaining to conflict between patients and their family caregivers in our review has been reported among groups not typically associated with palliative care.^{37,40–42} For example, distress for patients with overactive bladder syndrome and their family caregivers, can also lead to a lack of communication and limit mutual understanding between patients and family caregivers.⁴⁰ The emotional and physical burden of mental illness have also resulted in

feelings of conflict and ambivalence between patients and their family caregivers.⁴¹ Conflict among dyads in spinal cord injury can also arise because of difficulty negotiating new roles.⁴²

The findings of our review point to how patient and family caregiver support of one another in palliative care can be mediated by the wider family. Support from other family members can have a positive effect on both patients and family caregivers but a lack of support from other family members can be particularly stressful for family caregivers and make it more challenging for them in their caregiving role. These findings are consistent with palliative care literature.^{43,44} Understanding the processes of mutual support between patients and family caregivers in palliative care also needs attention to the wider social contexts of patients' and family caregivers' experiences in palliative care and how these contexts impact on how patients and family caregivers reciprocate in their support of one another. Support exchange between patients and family caregivers in palliative care is also mediated by contexts beyond the dyad that shape patients' and family caregivers' capacity to support each other.

Strengths and limitations

This review was limited to original peer-reviewed journal publications and excluded all grey literature. Although a search through grey literature might have identified additional evidence for this review, limiting our review to the above allowed us to assess objectively the methodological quality of each piece of evidence that we included. A wider 'scoping' review pertaining to mutual support between patients and family caregivers in palliative care would broaden further our understanding of this phenomenon.

Another limitation of this review is that we limited our inclusion to studies reporting on patients with clearly advancing conditions likely to result in their death. Palliative care can serve the needs of people with life-limiting or life-threatening illness at different stages of non-curable conditions. A systematic review of the evidence in palliative care along the full illness trajectory would serve to expand on our review findings. Due to the small number of studies which addressed this topic, in addition to studies that sampled both the patient and family caregiver, we included studies that sampled only patients or only family caregivers once the data generated pertained to mutual support or reciprocity between patients and family caregivers. Therefore, it is possible that in these studies, the evidence reflects only what patients or only what family caregivers perceived as mutual or reciprocal. Finally, we limited our review to a 20-year period. A review from inception to the end period could have extracted other studies that met other inclusion criteria.

What this review adds to existing knowledge

The findings of the review highlight the complex nature of relations between patients and family caregivers in palliative care. Shared understanding and positivity can enable patients and family caregivers adjust to progressive illness and engage effectively in the decision-making process. However, patients and family caregivers also experience distress and do not routinely communicate their concerns to each other. In some cases, disclosure can be more challenging for family caregivers. In practice, attention should focus not only on alleviating distress for patients and family caregivers but also on how patients and family caregivers can best communicate their distress to each other. Facilitating patients and family caregivers in this context has potential not only to alleviate distress for both patients and family caregivers but also to increase concordance between patients and family caregivers in the decision-making process.

Conclusions

The studies extracted in our review varied in scope and design. The small number of studies found to answer the review questions combined with broadly very different aims across studies makes it difficult to fully extrapolate findings of the review. Nonetheless, the findings from this review have some key implications for research and practice.

As stated, we found that none of the studies extracted reported exclusively on mutual support between patients and family caregivers in palliative care and that only one study had aimed from the outset to investigate processes of support and care between patients and family caregivers. A limited focus on *mutual* support between patients and family caregivers could in part be a consequence of how we traditionally conceptualise in research and practice the roles of patients and family caregivers in palliative care. Although patients and family in palliative care are treated by healthcare professionals and researchers as a 'unit' of care,^{45,46} more-often-than-not, patients in palliative care are defined as recipients of care from family caregivers, and family caregivers are defined as providers of support to patients. Research in palliative care that is sensitive to the bidirectional nature of support between patients and family caregivers and to the wider caring and family roles that patients and family caregivers can have in relation to each other, is needed to advance our understanding of mutual support between patients and family caregivers in palliative care.

Literature pertaining to mutual support between patients with advancing non-curable illness and their family caregivers in palliative care has reported primarily from people with cancer and/or their family caregivers. However, palliative care is not limited to people who live

with cancer and multiple other diagnostic groupings (e.g. neurodegenerative disease, chronic heart failure and chronic obstructive lung disease) access palliative care services. Studies pertaining to mutual support between patients with advanced illness and family caregivers in palliative care that extends to other conditions would be beneficial to expand on what we now know about mutual support between cancer patients and family caregivers in palliative care.

The findings suggest that support from the wider family can allow for greater emotional engagement between patients and family caregivers in palliative care and alleviate distress for family caregivers. However, family caregivers' perceived lack of support from other members of the family can make it more difficult for family caregivers to adjust to the demands of caregiving. Research to identify how the wider family can best support the patient and family caregiver in palliative care and alleviate distress for the family caregiver could be beneficial. Indeed, attention to wider socio-cultural contexts in palliative care is always necessary. Socio-cultural contexts (e.g. life-course trajectories, social inclusion) do shape the experience of death and dying,⁴⁷ which in turn can impact on mutuality between patients and family caregivers in palliative care.

Further research is required to identify key domains of mutual support between patients and family caregivers in palliative care. Understanding better what actions or interactions constitute mutual support between patients and family caregivers and the conditions that impact positively or negatively on patients' and family caregivers' abilities to support one another, can help guide interventions in palliative care focused on enabling supportive relations between patients and family caregivers.

Author contributions

G.F. conceived the study and supervised the work. G.F. and R.McC. designed the research strategy and screened studies. R.McC. extracted and synthesised the evidence. G.F. contributed to the synthesis. R.McC. wrote the manuscript and G.F. contributed to writing in all sections of the manuscript. R.McC. and K.R. commented on the design and research strategy. G.F., R.McC. and K.R. critically reviewed drafts for intellectual content. All authors read and approved the final manuscript.

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Supplemental material

Supplemental material for this article is available online.

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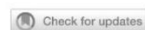
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(ii) Patient and caregiver reciprocal support: Impact on decision making in specialist palliative care. (McCauley et al., 2023b)

Original Article

Patient and Caregiver Reciprocal Support: Impact on Decision Making in Specialist Palliative Care



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Abstract

Context. Patients and informal caregivers in palliative care can reciprocate in supporting one another. However, how reciprocal support among patients and informal caregivers in palliative care impacts on their decision making for care is not well understood.

Objectives. To identify how reciprocal support among patients with advanced illness and their informal caregivers in specialist palliative care impacts on their decision making for care.

Methods. Between July 2021 and May 2022, 30 qualitative interviews were conducted with 14 patient and caregiver dyads, seven nondyad caregiver participants and one nondyad patient participant (total $n = 36$), recruited from a large regional specialist palliative care service. Data were analyzed using Corbin and Strauss grounded theory method.

Results. Reciprocal support among patients and informal caregivers was underpinned by obligation and choice. Caregivers who felt obliged to care had difficulty communicating with the patient about the patient's preferences for care and their own wishes for patient care. Patients who felt obliged to accept support from their caregiver tended to minimize caregiver participation in decision making which made caregivers feel disempowered in discussions about patient care. Caregivers tended to be more involved in decision making when caregivers assumed caregiving duties by choice and when the patient did not feel restricted by their reliance on their caregiver. Open communication between patients and caregivers made patients more trusting of their caregiver.

Conclusion. Patient and caregiver dyadic interventions in specialist palliative care involving decision making need to account for how obligation and choice manifest and function between the patient and caregiver. *J Pain Symptom Manage* 2023;66:570–577. © 2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Key Words

Decision making, support, reciprocity, patient, caregivers, qualitative, grounded theory

Key Message

This study investigated how patient and informal caregiver reciprocal support in specialist palliative care impacts on patient and caregiver decision making for care. The findings indicate that both obligation to each other and feeling constrained by one another can limit patient and caregiver open disclosure in decision making.

Introduction

People in receipt of specialist palliative care are typically patients whose palliative care needs are increasingly complex.^{1,2} Patients referred to specialist palliative care often present with more immediate palliative care needs and encounter challenging decisions about their care.³ Across jurisdictions, patients

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receiving specialist palliative care rely on informal caregivers (often referred to as family caregivers) for their care,^{4–7} and informal caregivers are involved to varying degrees in the decision-making process for patient care.⁸ Informal caregivers also make decisions about care in relation to their own needs, including for example, respite care.⁹

We know that patients and their informal caregivers in palliative care have capacity to reciprocate in supporting one another by each remaining positive for one another, by acknowledging each other's needs, and by jointly adapting to their changing roles.¹⁰ However, reciprocal support among patients and informal caregivers in palliative care in the context of making decisions about care, is poorly understood. Relationship conflict between patients and informal caregivers in palliative care including in specialist palliative care can result from a lack of communication about and awareness of each other's preferences for care.¹¹ That said, patients with advanced illness and their informal caregivers often conceal distress from one another with the aim of alleviating distress for one another¹² and make decisions about care in the context of their perceived obligations to one another.¹³ In our study, we sought to explain how reciprocal support among patients and informal caregivers in specialist palliative care impacts on their decision making for care. Understanding how supportive behaviors between patients and informal caregivers impacts on treatment decision-making is necessary to facilitate effective communication between patients and their caregivers, and in turn, optimize care outcomes for both the patient and caregiver.

Methods

Study Design

We used the grounded theory method¹⁴ for this study. The method is a systematic set of techniques and procedures to identify concepts and build theory from qualitative data.¹⁴ It is primarily an inductive qualitative approach which can be used to explain the phenomenon of interest^{14,15} (i.e., in this study, how reciprocal support among patients and informal caregivers impacts on their decision making for care). We used Corbin and Strauss grounded theory approach¹⁴ because we sought to explain at a substantive level, key processes and contexts^{14,15} which can underpin support between patients and caregivers in specialist palliative care and which subsequently impact on their decision making about care. We referred to the Standards for Reporting Qualitative Research (SRQR)¹⁶ to report this study.

Ethics Approval

Ethical approval to conduct the study was provided by the Faculty of Health Sciences Research Ethics

Committee of Trinity College Dublin, and by the Research Ethics Committee of St. Francis Hospice Dublin. Informed consent to participate in the study was provided by each participant.

Setting and Participants

We recruited 15 patients with advanced illness (cancer $n = 14$, neurodegenerative $n = 1$) and 21 informal caregivers from two hospice sites which constitute a large regional specialist palliative care service in the Republic of Ireland covering an area of ca. 700,000 people (14 % of the national population). Inclusion criteria for patients were that they be ≥ 18 years old and in receipt of specialist palliative care. Inclusion criteria for caregivers were that they were also ≥ 18 years old and that they were identified by a patient in receipt of specialist palliative care as their primary informal caregiver. As per grounded theory method, we moved back and forth between sampling, data collection and data analysis, and we ceased sampling when key categories were well described and dimensionalized¹⁴ (i.e., when new data was no longer adding further meaning to the key findings). Sampling was purposive^{15,17} to obtain variation among the sample (e.g., age and life stage of patients and caregivers, type of informal caregiver), and then theoretical based on the data generated.^{14,15,18} Recruitment took place between July 2021 and May 2022. Participants were recruited primarily through community specialist palliative care teams of the two hospice sites. Other avenues for recruitment from the regional specialist palliative care service such as outpatient clinics, day hospice, and inpatient hospice, were limited because of COVID-19 restrictions in place. The sample comprised 14 patient-caregiver dyads, and seven caregivers and one patient who were non-dyad participants (total $n = 36$). No patient participant or non-participating patient of a caregiver participant had a prognosis of >18 months. Tables 1, 2 and 3 outline the sample in detail.

Data Collection

Data collection comprised 30 semistructured interviews focused on the topic. Eight of the 14 dyads were interviewed separately (16 interviews), and the remaining six dyads were by their request, interviewed together (six interviews). The patient and the caregivers ($n = 8$) who participated without their respective other were each interviewed alone (eight interviews). The open-ended questions (Table 4) which formed the basis for interviews were informed by a systematic review of patient and caregiver mutual support in palliative care conducted by the group,¹⁰ wider literature on patient and caregiver relational decision-making in advanced illness,¹⁹ and by public and patient involvement (PPI). The PPI review of the study reported was undertaken by a member (former caregiver) of an

Table 1
Description of Participants and of Qualitative Interviews

P/CG Number	Dyad / Nondyad Participants	Relationship to CG/P	Condition (Patient Participant / Nonparticipating Patient)	Interviewed	Mode of Interview	Recruitment Source
P1	Dyad	Wife	Stage IV breast cancer	Together	Online video	SCPC
CG1		Husband		Together	Online video	
P2	Dyad	Husband	Progressive multiple sclerosis	Together	Phone	Inpatient hospice
CG2		Wife		Together	Phone	
P3	Dyad	Partner (M)	Stage IV lung cancer	Alone	Phone	SCPC
CG3		Partner (W)		Alone	Phone	
P4	Dyad	Mother	Stage IV Hodgkin's lymphoma	Alone	Phone	SCPC
CG4		Daughter		Alone	Phone	
P5	Dyad	Husband	Stage IV pancreatic cancer	Alone	Phone	SCPC
CG5		Wife		Alone	Phone	
P6	Dyad	Mother	Stage IV lung cancer	Together	Phone	SCPC
CG6		Daughter		Together	Phone	
P7	Dyad	Father	Stage IV liver cancer	Alone	Phone	SCPC
CG7		Daughter		Alone	Phone	
P8	Dyad	Husband	Stage IV lung cancer	Alone	In-person	SCPC
CG8		Wife		Alone	In-person	
P9	Dyad	Father	Stage IV stomach cancer	Together	In-person	SCPC
CG9		Daughter		Together	In person	
P10	Dyad	Husband	Stage III prostate cancer	Together	Phone	SCPC
CG10		Wife		Together	Phone	
P11	Dyad	Wife	Stage IV breast cancer	Alone	Phone	Inpatient hospice
CG11		Husband		Alone	Online video	
P12	Dyad	Husband	Stage IV lung cancer	Together	Phone	SCPC
CG12		Wife		Together	Phone	
P13	Dyad	Husband	Stage IV colorectal cancer	Alone	Phone	SCPC
CG13		Wife		Alone	Phone	
P14	Dyad	Father	Stage III colorectal cancer	Alone	Phone	SCPC
CG14		Daughter		Alone	Phone	
P15	Non-dyad	Husband	Stage IV lung cancer	Alone	Phone	SCPC
CG15	Non-dyad	Daughter	Stage III ovarian cancer	Alone	Phone	SCPC
P16	Non-dyad	Daughter	Stage III lung cancer	Alone	Phone	SCPC
CG17	Non-dyad	Husband	Stage IV lung cancer	Alone	Phone	SCPC
CG18	Non-dyad	Daughter	Cardiac failure	Alone	Phone	SCPC
CG19	Non-dyad	Daughter	Stage III lung cancer	Alone	Phone	Outpatient hospice
CG20	Non-dyad	Daughter	Stage III colorectal cancer	Alone	Phone	SCPC
CG21	Non-dyad	Son	Advanced bone cancer	Alone	Phone	SCPC

P = patient; CG = caregiver; SCPC = specialist community-based palliative care; M = man; W = woman.

established Irish-based palliative care PPI group. Twenty-seven of the 30 qualitative interviews were conducted remotely (25 interviews via phone and two interviews via the video-conferencing platform zoom²⁰) because of severe COVID-19 restrictions in place for in-person interviewing during periods of data collection. All participants had been given a choice of an online video-call for their interview using General Data Protection (GDPR) compliant platforms (e.g., Zoom, Microsoft Teams) but only three participants wished for this mode of interview. Interviews were audio-digitally recorded and were an average of 43 minutes in

duration. All interviews were transcribed. Transcribed interviews were then sent back to respective participants for member checking²¹ except for a minority of participants ($n = 4$) who preferred not to receive a copy of their transcript. No participants requested alteration to their transcript (i.e., data).

Data Analysis

The analysis of the dataset involved three stages of coding.¹⁴ Through constant comparison of the data, data were first open coded by breaking down and labelling data into codes and concepts (aggregation of codes) that captured incidents, patterns and behaviors that tentatively pointed to reciprocal support, and how patient and caregiver reciprocity comprised conditions that were shaping decision making for care. The next stage of coding referred to as conceptual saturation,¹⁴ involved building relationships between key concepts to form categories (highly developed concepts) that could identify processes of reciprocal support, account for variation in participant decision-making, and pinpoint more clearly key connections between reciprocal

Table 2
Participant Patient and Caregiver Gender and age (Range and Median)

Gender	($n = 36$)	Age Range (Years)	Median Age
Women patients	4	40–77	58 years
Men patients	11	46–90	67.5 years
Women caregivers	17	22–80	51.5 years
Men caregivers	4	43–70	57 years

Table 3
Patient and Caregiver Relationship

Patient	(n = 15)
Spouse/partner of caregiver	10
Parent of caregiver	5
Caregiver	(n = 21)
Spouse/partner of patient	10
Adult child of patient	11

support and decision making. For example, by the mid-stage of data collection, obligation was emerging as a key category which comprised in part, participants believing it necessary to support their respective other. Obligation also included participants feeling constrained in their relationship with their respective other because they sometimes felt obliged to agree with their respective other's preferences for care. We then sampled patients and caregivers who had already communicated disagreement about their preferences to further dimensionalize the concepts of obligation and choice, and understand relationships between obligation, choice, and decision making. The final stage of coding (theoretical integration)¹⁴ focused on integrating key categories to explain patient and caregiver reciprocal support and how their reciprocity impacted on their decision making for care. Author RMCC conducted the analysis and used the qualitative data

Table 4
Interview Open-Ended Questions

Patient
What are your experiences so far of palliative care with (caregiver)?
How do you think both of you are coping?
What do you think is the best kind of help or support to get from (caregiver)?
What makes it difficult or easy to accept support from (caregiver)?
How would you describe the way you rely (or might not rely) on (caregiver)?
In what way(s) do you feel you are a support (or not) to (caregiver)?
What do you think is the best kind of help or support that you give or can give to (caregiver)?
How might what you want for your care be influenced by what you think is best for (caregiver)?
How might your responsibility to (caregiver) impact your preference for care and how you decide about your care?
Is there anything else you would like to say that you have not had an opportunity to say?
Caregiver
What are your experiences so far of palliative care with (patient)?
How do you think both of you are coping?
In what way(s) do you feel you are a support (or not) to (patient)?
What do you think is the best kind of help or support that you give or can give to (patient)?
What makes it difficult or easy to provide help to (patient)?
What do you think is the best kind of help or support that (patient) provides or can provide to you?
How would you describe the way you rely (or might not rely) on (patient)?
How might what you want for (patient's) care and for your own care be influenced by what you think is best for (patient)?
How might your responsibility to (patient) impact your preferences for care?
Is there anything else you would like to say that you have not had an opportunity to say?

analysis software NVivo12 to assist with coding the data. Notes and analytical memos were also compiled by RMCC to aid the analysis. The data were examined by author GF to increase rigor (trustworthiness) in the analysis. Rigor was also ensured by regular and systematic debriefing between RMCC and GF during data collection and analysis.

Results

Here, we report on key categories from our data—choice and obligation, which underpinned reciprocal support among patients and informal caregivers. We explain how reciprocal support impacted on patient and caregiver decision making for care in the context of both obligation and choice. Data extracts (i.e., participants' quotations) are tagged with the participant ID code from Table 1 with "P" indicating patient and "CG" indicating caregiver.

Reciprocal Support: Choice and Obligation

Informal caregivers assumed a caregiving role by their own choice or else felt obliged to provide care to their ill family member. Feeling obliged to provide care was associated with the absence or lack of other family members to provide care. Participant CG4 who provided care to her mother of her own accord and participant CG14 who was obliged to provide care to her father in the absence of other family support, communicated:

The reason I'm doing it [caregiving] is because I myself want this part of her life to be a nice part for her. I want this part of her life to be as happy as all the other parts have been. (CG4)

I'm the only daughter... I would have always been the one who does the most caregiving... It was a natural progression from bringing him [patient] to appointments to being his caregiver because my brother does very little... very caught up in his own life. I would prefer more support and over time, I have asked for more support [from brother] and it doesn't come to fruition. So, rather than resent it, I just deal with it. (CG14)

Caregivers provided support in multiple ways, ranging between physical, psychological, emotional, and financial. However, patients' reciprocation of support was primarily confined to emotional support to their caregiver to compensate for loss of ability to reciprocate in domains of care in which they now felt less able. Patients themselves felt they were limited in choice with respect to the type of support they could provide to their caregiver because of their own deteriorating health. For example, participant P3 shared that he provided emotional support to his caregiver in the context

that providing support other than emotional support was increasingly difficult for him:

I am trying to help as much as I can but it's getting where I don't have the energy, [but] we're still an emotional support for each other ... We're one hundred percent behind each other.

Patient and caregiver penchant to receiving support from one another was also shaped by choice and obligation. Some patients who were distressed by deterioration in their condition felt not only constrained in a care recipient role but also obliged to accept support because of their reliance on their caregiver:

So I know I'm going to die ... and nobody can do anything for me [to prevent that] ... She [caregiver] brings me everywhere now ... to [healthcare] meetings ... but I really don't want to rely on her. (P14)

For caregivers, those who felt they had choice in being a caregiver were more receptive to supportive behaviors from their ill family member, when compared to those who felt they had little choice but to provide care to their ill family member. For example, participant CG4 who had by her own accord taken responsibility to care for her mother stated:

For me it's easy [by choice] to do everything for her ... even though she is sick, dying, she is still trying to help you work through your stupid, little problems, she still makes sure that you are okay.

Caregivers who felt they had limited choice in a caregiving role often reported conflict in their relationship with their ill family member. Caregiver perceived lack of control in a caregiving role combined with patient and caregiver relationship conflict resulted in some cases, the caregiver not considering support from the person they cared for. For example, CG21 who had already indicated an absence of control in the role of caregiver to his mother communicated:

She always has been quite a difficult person to live with over the years ... She doesn't do praise, she does complaining and I'm going to be told I am doing it [caring] wrong ... I would probably say now that I do it (care) with less joy in my heart ... [so] I don't think about getting support [from patient].

Providing and Receiving Support in the Context of Obligation: Impact on Decision Making

Caregivers who assumed informal caregiving duties predominantly out of obligation to the patient approached decision making differently to caregivers who felt that their caregiving was without obligation. Caregivers who felt obliged to care reported difficulty in discussing with the patient the patient's preferences

for care and their own wishes for patient care. They also, in some cases, struggled to engage in conversations with the patient about treatment options. For example, participant CG21 who felt highly obligated to care stated:

When she [patient] got cancer, she just point-blank refused to have surgery ... I try and make, you know, a considered evaluation of what's being offered ... [but] it would be difficult to discuss with her what was better.

Caregivers who felt obliged to take on a caregiving role were those who reported most distress in their role. Obligation to care was associated with caregivers feeling burdened in their role and feeling under strain led them to want to engage more with healthcare professionals than they did with the patient. Participant CG#19 who reported significant strain in a caregiving role reported:

It can be like having a baby sometimes, I can't go anywhere ... [but] I'm not going to overrule what she wants. I can always go and talk to the doctor who is great for giving information. She will tend to listen to him.

However, patients who felt obliged to accept support from their caregiver (underpinned by loss of control over their own abilities), wanted to minimize caregiver participation in the decision-making process for care, preferring to discuss treatment options and plan for future care with healthcare professionals without direct input from their caregiver. Participant P8 who had felt under obligation to his caregiver stated:

I think my family [caregiver] look up cancer and they look up stage four, and they become experts! They know nothing! ... I would leave advice to the experts.

Subsequently, patient minimization of the caregiver involvement in decision making made caregivers feel disempowered in discussions about patient care or feel resigned to supporting the patient's decisions about their care even if they disagreed with the patient's choices and preferences for care:

If we were in the doctors and we had to make a decision on what to take or what to do ... he [patient] has his own answer in his head ... I'm not going to say no or that I'm not happy with a certain decision or the way something is going. If it was what he wanted I wouldn't argue. (CG7)

Providing and Receiving Support in the Context of Choice: Impact on Decision Making

Caregivers who felt they supported their ill family member by their own choice and without obligation tended to be invited by the patient into the decision-making process for care. Communication with healthcare professionals in these situations involved both the

patient and caregiver together. Participant CG1 and participant P4 voiced with satisfaction:

I suppose any of the suggestions that have been put to us in medical appointments, there would always be some sort of dialogue between us about it ... I like to be involved with certain things. What I do is kind of research everything to the utmost degree as such and take the best of the information out of it ... and then we would all sit down and speak about it ... just to have that opportunity there to both jointly make that decision ... It's incredibly uplifting. (CG1)

Everyone wants the best for me ... so I would ask [caregiver] for a bit of advice and listen to the nurses. (P4)

In situations where the caregiver did not feel forced into providing care and where the patient did not feel inhibited by their reliance on their caregiver, patients and caregivers felt able to openly communicate their needs and preferences for care to one another. For example, participant CG2 who of her own accord took on a primary caregiving role, and participant P15 who did not feel restricted by dependence on his caregiver, communicated:

Each of us can talk about our needs ... I can converse with him [patient] and although he does what he thinks is right, he will always ask us [family]. (CG2)

We make decisions together and [caregiver] will always say "Look, try it [chemotherapy] out" because she doesn't want me to die. But I'm going through the treatment so, usually she will say ... "It's your body so whatever you decide to do I'll go with it." (P15)

Open communication between patients and caregivers resulted in patients placing increased trust in their caregiver's opinion and in some cases, made patients feel more trusting of their caregiver's judgement than their own judgement about their care. Patient full trust in caregivers often placed the responsibility of decision making primarily on the caregiver. For example, participant P1 disclosed to her caregiver (CG1) in their interview:

I would trust [caregiver] to make the best decision for me ... I trust him deeply, that you [speaking to caregiver] know, if you're saying that this is going to do me good. I trust you completely on that.

Overall, when caregivers did not feel under duress to provide informal care to the patient and when the patient was not constrained by their dependence on their caregiver, caregivers' desire to be involved in decision making was heeded by the patient.

Discussion

To our knowledge, this study is the first to report how reciprocal support among patients and informal caregivers in specialist palliative care impacts directly on how both approach decision making in relation to care. Decision making was shaped by feelings of obligation to give and receive support, and by choice (or lack of choice) patients and caregivers felt they had in their respective roles and in relation to each other. Obligation had negative connotations²² for both patients and caregivers.

We know that although patients and caregivers in palliative care can feel constrained in their respective roles,^{23,24} they also prioritize each other's needs over their own out of obligation to one another.¹³ In the current study, we have identified how obligation functioned between patients and caregivers including how it shaped their decision making for care. Obligation was not necessarily an antecedent to or a consequence of a particular need to support one another. Rather, feelings of obligation on the part of both the patient and caregiver arose when they felt they had less choice either as a provider of support to or as a recipient of support from one another.

The findings have implications for shared decision-making in palliative care including specialist palliative care.^{25,26} Shared decision-making in palliative care typically involves informal caregivers in discussions about care.^{27,28} We identified that patient and caregiver obligation did not result in open communication about each other's preferences for care, but instead made patients want to limit caregiver participation in decision making. However, when patients felt less obliged to accept support from their caregiver or felt less constrained despite their reliance on their caregiver, patients and caregivers were more collective in the decision-making process for care. Caregiver involvement in decision making when actively encouraged by the patient resulted in some patients placing more value on their caregiver preference or judgement than their own which has implications for safeguarding patient autonomy^{29,30} when making decisions about care.

A primary strength of the study is that we have expanded key understandings in palliative care of how patients with advanced illness and informal caregivers make decisions about care in the context of their perceived responsibility to one another. Recruitment was from a large regional specialist palliative care service and the transferability³¹ of the findings in this qualitative study allow for comparisons across different contexts in specialist palliative care. However, we did not capture change in either patients' or caregivers' status given that data collection occurred at one point in time for each participant. Neither did we set out to explore

issues around a specific set of treatment or care decisions. In addition, whilst many caregivers reported high levels of carer burden, we did not ask caregivers to formally rate the intensity of their caregiving. Caregivers' perceptions surrounding the intensity of their caregiving may impact on how they engage in decision making. A minority of participants participated without their respective other. In these instances, this may have reduced how much their interview data were contextualized to their respective other. Qualitative interviews in data collection were limited primarily to remote qualitative interviews by phone due to restrictions imposed by Covid-19. More in-person or video-based online interviews (i.e., face-to-face interviews) would have allowed for observation of participants in the interview setting to further contextualize their perspective. Lastly, in Ireland, there has been a tradition of family-based decision making in palliative care, but also in more recent decades, reduced societal expectations that family be involved in decision making or indeed provide support and care. The findings are representative of the cultural context in which participants participated.

Conclusions

Our study is evidence that patients and informal caregivers in specialist palliative care can be mutually supportive out of obligation to one another. However, obligation and feeling constrained by one another can limit patient and caregiver open disclosure in decision making. The findings inform the development and delivery of patient and caregiver dyadic interventions in specialist palliative care which incorporate focus on supporting patients and caregivers in the decision-making process for care. It is beneficial to consider, particularly, the relevance of control and choice for both the patient and caregiver in their relationship and communication with one another. Overall, participants' interpretations of obligation were rooted in more contemporary Western understandings of obligation. Studies conducted in non-Western cultures focused on reciprocal support among patients and informal caregivers and how reciprocal support impacts on their approach to decision making would be beneficial to compare.

Authors' Contributions

GF designed the study, obtained funding to conduct the study, supervised the research, assisted with interpretation of the data, and wrote the manuscript. RMcC communicated with gatekeepers, recruited participants, collected the data, transcribed the interviews, analyzed the data, and contributed to the write up of the manuscript. KR and RMcQ facilitated recruitment, advised on recruitment strategies, and made critical

contributions to the manuscript. All authors reviewed and commented on the final draft. All authors approved the final draft.

Disclosures and Acknowledgements

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(iii) **Supportive relationships between patients and family caregivers in specialist palliative care: a qualitative study of barriers and facilitators (McCauley et al., 2023c)**

Qualitative & mixed methods

Supportive relationships between patients and family caregivers in specialist palliative care: a qualitative study of barriers and facilitators

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ABSTRACT

Objectives Patients with advanced illness and their family caregivers can be mutually supportive. However, what facilitates and/or restricts supportive relationships between patients and family caregivers in palliative care remains unclear. We aimed to identify key barriers to and facilitators of supportive relationships between people with advanced illness and family caregivers in specialist palliative care.

Methods A qualitative study using grounded theory methodology was conducted. Semistructured interviews were undertaken with 15 patients with advanced illness and 21 family caregivers purposively and theoretically sampled from a large regional specialist palliative care service. Verbatim transcripts were analysed in line with grounded theory coding procedures.

Results Mutual support was underpinned by mutual concern and understanding. Facilitators of supportive relationships included patients and family caregivers already having a close relationship, caregivers assuming caregiving duties by choice, caregivers feeling competent in a caregiving role, patients valuing caregiver efforts, availability of respite for the caregiver and direct support from healthcare professionals to help both patients and caregivers adjust to advanced illness. Barriers to supportive relationships included absence of support from the wider family, prior mutual conflict between the patient and caregiver, caregivers feeling constrained in their caregiving role and patient and caregiver distress induced by mutual loss.

Conclusions Multiple factors at both a micro (eg, relationship based) and mesolevel (eg, assistance from services) impact patient and family caregiver ability to support one another in specialist palliative care. Supportive relationships between patients and family caregivers are

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Patients with advanced illness and their family caregivers in palliative care can be mutually supportive through open disclosure and by jointly adapting to changing roles.

WHAT THIS STUDY ADDS

⇒ Support from both healthcare professionals and the wider family facilitates supportive relationships between patients and family caregivers in specialist palliative care.
⇒ Assuming caregiving duties by choice and being valued by their ill family member makes family caregivers in specialist palliative care feel competent in a caring role and fosters support between them and the patient.
⇒ Pre-existing conflict and distress induced by mutual loss can make it challenging for patients and family caregivers in specialist palliative care to feel effective as a source of support to one another.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Healthcare professionals in specialist palliative care have capacity to increase supportive relationships between patients and family caregivers through patient–family caregiver dyadic interventions focused on enabling control and adapting to mutual loss.

mediated by feelings pertaining to both control and loss.

INTRODUCTION

Research has focused on the role and benefit of the family caregiver in providing care and support to people with advanced illness in palliative care, including

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specialist palliative care.^{1,2} Provision of support by family caregivers to patients in palliative care takes multiple forms, ranging between direct physical and emotional care, to advocating for patient services and coordinating care for the patient.³ The impact of caring on the family caregiver, including both potential burdens and beneficial outcomes for family caregivers in specialist palliative care is documented.^{4,5}

In most existing studies in palliative care to date, people with advanced illness tend not to be defined from the outset as key providers of support to their family caregivers.⁶ However, examination of the patient and family caregiver relationship in advanced illness has identified that patients and family caregivers have capacity to reciprocate in the provision of support to one another.^{7,8} A systematic review of the limited evidence on mutual support between patients with advanced illness and family caregivers in palliative care⁹ identified that patients and family caregivers can support one another through mutual and open disclosure, mutual recognition of the challenges they face and by jointly adapting to change in roles in the context of advanced illness. The absence of mutual disclosure in relation to distress was highlighted as a source of conflict between patients and family caregivers.⁹

Evidence points to the positive effects of dyadic psychosocial and psychoeducational interventions for patients and family caregivers in advanced stages of illness^{10–12} including in a specialist palliative care setting.¹² Such interventions have included strategies for communication, joint problem solving and maintaining relationships.^{10–12} They have also included strategies to help patients and family caregivers understand their choices in relation to each other and within the constraints and possibilities of their situation.¹² These interventions have shown positive effects on caregiver burden,¹¹ patient and caregiver quality of life,¹¹ patient and caregiver anxiety, and distress,^{10–12} patient and caregiver competence and relatedness,¹⁰ and patient and caregiver self-efficacy.¹¹ However, what facilitates and/or restricts supportive relationships between patients with advanced illness and family caregivers in palliative care remains unclear.⁹ In this study, we, therefore, aimed to identify key barriers to and facilitators of supportive relationships between people with advanced illness and family caregivers in specialist palliative care.

METHODS

We conducted a qualitative study using a grounded theory approach¹³ to investigate key dimensions of mutual support between patients and family caregivers in specialist palliative care including facilitators of and barriers to supportive relationships between them. The grounded theory method comprises both inductive and abductive analytical strategies to generate substantive data and explanatory frameworks that can explain psychosocial processes^{13,14} (in this case, supportive

relationships between patients with advanced illness and family caregivers). We used a grounded theory approach¹³ because we sought to explain at a substantive level, key actions, behaviours and contexts which can explain the phenomenon of interest (factors that enable and/or restrict supportive relationships between patients and family caregivers in specialist palliative care). The epistemological underpinnings of the approach taken are rooted in symbolic interactionism, a broad sociological theory which emphasises that the way in which people construct meaning is influenced by their interaction with others. We referred to the Standards for Reporting Qualitative Research¹⁵ to report this study.

Setting and recruitment

Participants were recruited from two hospice sites in the Republic of Ireland which together constitute a large regional specialist palliative care service covering a catchment of approximately 700 000 people (circa 14% of the national population). The palliative care service provides a mix of inpatient, outpatient, day hospice and community-based care. Inclusion criteria for patient participants were: a formal diagnosis of a life-limiting condition(s), ≥18 years of age, able to provide informed consent and in receipt of specialist palliative care. Inclusion criteria for family caregivers were: ≥18 years of age, able to provide informed consent and identified by a patient in receipt of specialist palliative care as their primary caregiver. The term 'life-limiting condition' was understood by the research team as an incurable condition that would shorten a person's life. Our definition of family caregiver for this study was not restricted to familial-based relationships but rather extended to any category of significant other who was identified as a primary caregiver. Gatekeepers at both hospice sites assisted with recruitment by informing potential participants about the study. Interested participants were then provided with detailed participant information leaflets by the investigators. Each participant gave informed consent to participate in the study.

While we primarily sought to recruit patient–family caregiver dyads, we were conscious at the outset of the study that fully restricting participation only to dyads might push the sample towards the more consensual dyad (eg, the possibility of a patient and family caregiver not wanting to participate together if they were undergoing major conflict or disagreement). Sampling and analytical procedures¹³ allowed for the possibility to incorporate variation as required. Recruitment took place between July 2021 and May 2022.

Sampling

Participants were initially purposively sampled for variation (eg, age, life stage, gender and variation in patient and family caregiver relationship), and then in later stages of the study theoretically sampled based

on key findings in the data.¹³ We ceased sampling when key findings that emerged from the data were saturated for meaning and incorporated variation to explain the data (in grounded theory terms, when no new data were extending our theoretical and integrative understanding of the data).¹⁴

Data collection

Semistructured interview schedules containing open-ended questions were formulated and informed by a systematic review of the evidence on mutual support between patients and family caregivers in palliative care already conducted by the authors⁹ and by wider literature pertaining to supportive relationships between patients and family caregivers in advanced illness, including sources identified by the last author on how patients and caregivers in palliative care can reciprocate in support of one another.⁶ Questions were also informed by public and patient involvement (PPI) at the design stage of the study. The PPI review of the study reported was undertaken by a member (former caregiver) of an established Irish-based palliative care PPI group. The semistructured interview guides were devised to capture contexts and processes.¹³ The interview guides allowed for consistency in data collection and the open-ended questions served as a platform for subsequent probing, prompting and clarifying questions to further interrogate data as the study proceeded.¹⁶ Interview schedules are available in online supplemental appendix 1.

Our initial protocol was for interviews to be in-person. However, we had to adjust procedures to facilitate remote interviewing as restrictions imposed by COVID-19 reduced the possibility in most cases for in-person interviews. RMcCauley transcribed all interviews verbatim prior to analysis. A copy of each transcript was then returned for the purpose of member checking to respective participants except for four participants who did not wish to receive their transcript. No participant requested alteration to their data. RMcCauley also recorded field notes after each interview to help contextualise the interview data.

Data analysis

The data were analysed using the constant comparison technique.¹⁷ First, the data were open coded,¹³ which means broken down into codes and concepts (aggregation of similar codes) that captured key incidents, events and patterns that tentatively pointed to mutual support including barriers and/or facilitators to supportive relationships between patients and family caregivers. Data were then coded to achieve conceptual saturation,¹³ which involved building categories from identifying relationships between concepts and accounting for actions/interactions and/or behaviours in similar and different contexts. For example, in the early to mid-stage of data collection, few patients and family caregivers reported dissatisfaction with each

other. At this point, 'obligation' had emerged as a category which constituted feeling a need to support one another but *also* in some cases, family caregivers feeling constrained by having no choice but to support their ill family member. We then (theoretically) sampled some participants where there was known tension in their relationship to better account for how obligation functioned between patients and family caregivers.

The final stage of analysis involved a theoretical integration¹³ of the data to fully link key barriers and facilitators. Analysis of data at this point focused on mapping out fully saturated categories and their relationships (which had derived from across the dataset) to decipher key behaviours and contexts that comprised and explained the nature of supportive relationships between patients and family caregivers. This final stage of analysis enabled us to ascertain how and why supportive relationships between patients and family caregivers could be hindered and/or facilitated. The sampling and analytical procedures used¹³ allowed for constant comparison of data across the dataset (not limited only to comparison within, between or across dyads). Both descriptive and theoretical memos were formulated by RMcCauley at key stages of the analysis which together with coding, comprised an audit trail of the analysis. Rigour was enhanced through peer debriefing and cross-checking of data between RMcCauley and GF. The final narrative was reviewed and refined by the whole team. The NVivo qualitative data analysis software (.12) was used as a tool to code and manage the data.

RESULTS

Participant characteristics

The participants were 15 patients (n=14 cancer, n=1 neurodegenerative disease) and 21 family caregivers. The sample comprised 14 patient-family caregiver dyads, seven family caregivers who participated as non-dyad participants, and one patient who also participated without their respective other. Family caregivers participated on their own when the patient's health status deteriorated between investigators' initial approach and the scheduling of interviews to the point that the patient felt too unwell to participate. For the one patient who participated without their family caregiver, the family caregiver had declined to participate because of her own distress.

The sample was primarily suburban based. The majority of patient participants were men (11 out of 15) and the majority of family caregiver participants were women (17 out of 21). Most of the patient participants and the non-participating patients of participating family caregivers had advanced cancer. The average age of patient participants was 64.9 years, and the average age of family caregiver participants was 52.5 years. No patient participant or non-participating patient of a participating family caregiver were deemed by their medical team to have a prognosis

Table 1 Summary of participants

Participant	Relationship to FCG/P	Dyad/non-dyad participants	Participant age	Diagnosis of patient participant/patient cared for by FCG	Recruitment source—care setting	Urban/suburban/non-urban
P1	Wife	Dyad	40	Stage IV breast cancer	SCPC	Suburban
FCG1	Husband		43			Suburban
P2	Husband	Dyad	46	Progressive multiple sclerosis	Inpatient hospice	Suburban
FCG2	Wife		45			Suburban
P3	Partner (M)	Dyad	64	Stage IV lung cancer	SCPC	Suburban
FCG3	Partner (W)		64			Suburban
P4	Mother	Dyad	77	Stage IV Hodgkin's lymphoma	SCPC	Suburban
FCG4	Daughter		48			Suburban
P5	Husband	Dyad	62	Stage IV pancreatic cancer	SCPC	Suburban
FCG5	Wife		60			Suburban
P6	Mother	Dyad	57	Stage IV lung cancer	SCPC	Suburban
FCG6	Daughter		26			Suburban
P7	Father	Dyad	54	Stage IV liver cancer	SCPC	Suburban
FCG7	Daughter		22			Suburban
P8	Husband	Dyad	70	Stage IV lung cancer	SCPC	Suburban
FCG8	Wife		67			Suburban
P9	Father	Dyad	90	Stage IV stomach cancer	SCPC	Urban
FCG9	Daughter		52			Urban
P10	Husband	Dyad	83	Stage III prostate cancer	SCPC	Suburban
FCG10	Wife		80			Suburban
P11	Wife	Dyad	58	Stage IV breast cancer	Inpatient hospice	Urban
FCG11	Husband		62			Suburban
P12	Husband	Dyad	61	Stage IV lung cancer	SCPC	Suburban
FCG12	Wife		60			Suburban
P13	Husband	Dyad	72	Stage IV colorectal cancer	SCPC	Suburban
FCG13	Wife		68			Suburban
P14	Father	Dyad	72	Stage III Colorectal cancer	SCPC	Suburban
FCG14	Daughter		42			Non-urban
P15	Husband	Participating without other	68	Stage IV lung cancer	SCPC	Suburban
FCG15	Daughter	Participating without other	61	Stage III ovarian cancer	SCPC	Suburban
FCG16	Daughter	Participating without other	43	Stage III lung cancer	SCPC	Suburban
FCG17	Husband	Participating without other	70	Stage IV lung cancer	SCPC	Urban
FCG18	Daughter	Participating without other	52	Cardiac failure	SCPC	Suburban
FCG19	Daughter	Participating without other	44	Stage III lung cancer	Outpatient hospice	Suburban
FCG20	Daughter	Participating without other	41	Stage III colorectal cancer	SCPC	Suburban
FCG21	Son	Participating without other	54	Advanced bone cancer	SCPC	Suburban

FCG, family caregiver; M, man; P, patient; SCPC, specialist community palliative care; W, woman.

of >18 months at time of the patient and/or caregiver participation. The majority of the 15 patient participants (n=9) had already ceased full, active treatment (eg, radiation therapy, chemotherapy). All family caregivers were actively providing care to their respective other to assist the patient in everyday activities. The majority of the 36 participants were recruited via the community (ie, home-based) specialist palliative care service as other locations at point of recruitment (eg, outpatient and day hospice services) were affected by periods of COVID-19 restrictions. Table 1 provides a detailed summary of participants.

Description of the dataset

The 15 patients and 21 family caregivers participated in 30 qualitative interviews (table 2). Interviews were conducted with 8 of 14 patient–family caregiver dyads separately (ie, each member of the dyad interviewed on their own), and 6 dyads requested that they be interviewed together (ie, both patient and family caregiver in one interview). The seven family caregivers and the patient who participated without their respective other were each interviewed alone. Twenty-seven of the 30 interviews were conducted remotely: 25 by phone and the remaining two by the videoconferencing platform

Table 2 Mode of interview for data collection

P/FCG	Interviewed together/alone	Mode of interview
P1	Together	Zoom audio and video
FCG1	Together	Zoom audio and video
P2	Together	Phone
FCG2	Together	Phone
P3	Alone	Phone
FCG3	Alone	Phone
P4	Alone	Phone
FCG4	Alone	Phone
P5	Alone	Phone
FCG5	Alone	Phone
P6	Together	Phone
FCG6	Together	Phone
P7	Alone	Phone
FCG7	Alone	Phone
P8	Alone	In person
FCG8	Alone	In person
P9	Together	In person
FCG9	Together	In person
P10	Together	Phone
FCG10	Together	Phone
P11	Alone	Phone
FCG11	Alone	Zoom audio and video
P12	Together	Phone
FCG12	Together	Phone
P13	Alone	Phone
FCG13	Alone	Phone
P14	Alone	Phone
FCG14	Alone	Phone
P15	Alone	Phone
FCG15	Alone	Phone
FCG16	Alone	Phone
FCG17	Alone	Phone
FCG18	Alone	Phone
FCG19	Alone	Phone
FCG20	Alone	Phone
FCG21	Alone	Phone
Total=30 interviews		
FCG, family caregiver; P, patient.		

Zoom.¹⁸ All participants were offered the option of a video-based online interview¹⁹ but only a small minority of participants chose this. The average duration of interviews was 43 min, and each interview was digitally recorded.

Here, we report key dimensions of mutual support between patients and family caregivers followed by facilitators of supportive relationships between patients and caregivers and barriers to these relationships. Data extracts are tagged with the unique participant ID code, with 'FCG' indicating family caregiver and 'P' indicating patient; shared numeric identifiers indicate a patient-caregiver dyad except for P15 and FCG15 who were non-dyad participants.

Key dimensions of mutual support between patients and family caregivers

We ascertained primarily two forms of mutual support between patients and family caregivers. First, patients and caregivers reciprocated in emotional support of one another because they were aware of the other person's psychological distress living with the challenges of advanced patient illness. A caregiver and patient stated, respectively:

A lot of my issues would be how [patient] is doing emotionally ... I am coming to terms with situation for him ... I just find that when [patient] is in a good place, it takes an awful lot of [his] anxiety away. (FCG2)

My sense of trying to support [family caregiver], if I can show her that I am fighting this and that I'm well and happy, that seems to be one of the things she needs from me, and also to check in with her that she has somebody that she can speak with. (P2)

Second, mutual support involved reciprocation through different modes of support. In many cases, patients were unable to reciprocate in physical care or to sufficiently engage in instrumental activities of daily living for their caregiver. Instead, patients provided emotional support (eg, listening, reassuring) in lieu of other supports they no longer felt able to provide. A patient and caregiver conversed:

I get a bit lethargic. I get tired ... [But] there are certain things that I can still do to help the situation with [family caregiver]. (P10)

[To patient:] I think the best support you give me is you listen to me. (FCG10)

In some cases, patients felt that the support they provided might not necessarily be proportionate to the support they received from their family caregiver given their worsening health status. However, in these cases, caregivers still valued support from their respective other:

I can see that he knows I'm doing a lot for him ... and he does always say to me "I always appreciate what you are doing for me" ... and he does always try to reassure me and that's nice to hear as well. (FCG16)

To attend to the needs of one another, understanding one another's perspective was important for both patients and family caregivers. Indeed, mutual understanding was often key to patients and caregivers feeling able to support their respective other:

We are an emotional support for each other because we understand each other ... We are singing from the same hymn sheet ... understanding of one another and the way each other handles things and copes with things. (P3)

Overall, mutual support between patients and family caregivers was underpinned by patient and caregiver concern and regard for one another:

She [patient] is the most important person ... But she's also worried about me ... I'm the person she wants to see and she's the person I want to see. (FCG11)

Facilitators of supportive relationships

A strong premorbid relationship between the patient and family caregiver was generally perceived by participants to foster supportive relationships when confronted with the challenges of life-limiting illness. Pre-existing closeness and understandings of one another's habitual behaviours helped both patients and family caregivers cope with advanced illness:

We have had that close relationship, like through our entire lives so it wasn't difficult on the way in that sense. But like decisions and talking about things, and obviously I think we've gotten even closer since the diagnosis. (FCG6)

We have always been so close and a unit ... I can't hide anything from [family caregiver]. She knows my moods and can tell if there's something wrong with me ... she could tell right away. (P7)

The importance of strong premorbid relationships was observed particularly among patients and family caregivers who were spouses and who had already navigated life together and raised children. The experience of having already raised a family together provided a sound foundation for ongoing partnership in times of adversity. It also provided reassurance that they would face issues together and work as a team to deal with problems. For example, a caregiver shared:

The effort of the two of us [raising family] means we are far greater [stronger] and it helps ... that realisation ... It's a great relief to know that, oh my, that's okay, we will manage this together. (FCG10)

Supportive relationships between patients and family caregivers were also strengthened when non-spousal family caregivers nominated themselves to act as caregiver. Assuming caregiving responsibilities by choice, often in return for receiving support in the past, motivated caregivers to provide support to their ill family member. Caregiver FCG6 communicated:

I want to help my mom because she's done so much for us [family] as a single parent, like she was always there, so I think that would be nice to return the favour ... me and my sister help out and be a carer. That wouldn't be an issue.

Family caregivers were sustained in their ability to provide care by feeling competent and satisfied in their caregiving role. Feeling competent in a caregiving role was necessary for caregivers to manage their distress and help ease tension in their relationship with the patient. Of note, gratitude from the person they cared for was important for caregivers:

She does say to me ... "I don't know what I'd do without you" ... She does say "I'm a burden on you"

... but she does appreciate that we try our best for her and she knows that we do try our best. (FCG18)

Respite for family caregivers mainly in the form of time to engage in non-caregiving activities was also important for both patients and family caregivers to feel effective in a supportive role. Patients were for the most part acutely aware of the burden they felt they imposed on their caregivers and encouraged caregivers to avail of respite that could alleviate caregiver burden:

I want to make sure she [family caregiver] is okay and get them all [other family] to look after her if she needs help or anything. (P13)

However, support from the wider family (other family members who were not the primary family caregiver) was necessary to allow caregivers and patients spend time apart and re-energise caregivers in their supportive role:

I have always gone to the gym more so for my mental health than my physical health, so I still do that whilst [family member] is with her [patient]. We need that [family assistance] and I feel if I have done that [taken respite], I can look after her. (FCG20)

Lastly, direct support from healthcare professionals was important in facilitating patients and family caregivers to be of support to one another. Both patients and caregivers valued support from specialist palliative care services, particularly in situations when they both needed assistance to cope:

We are doing extremely well ... like we have had a lot of positive feedback, a lot of helpful input that's given us information, that has given us the ability to deal with a lot of things together day to day. (FCG1)

I came home [from hospital] and they [specialist community palliative care] were quick on the scene ... [family caregiver] was not sure how to be taking it and they took her aside ... gave her an idea of what's going on ... That was helpful. (P3)

Barriers to supportive relationships

A lack of assistance from other family members was a key barrier to supportive relationships between patients and family caregivers. Absence of support from other family members resulted in some caregivers feeling acutely distressed and then less able to provide the level of support and care they felt was needed by the patient. For example, one caregiver who was responsible for her ill-family member's care without additional informal care from other family members reported:

I find I am under a good bit of pressure now with her [patient] ... because obviously I want to do everything I can for her and everything she wants ... She was saying I want my hair done and my nails done, and I want my eyebrows done and I want new clothes and I just feel she's wanting loads from me at the moment ... So, it can be quite hard. (FCG4)

In some cases, family caregiver distress in the absence of other family support limited open communication between patients and caregivers. For instance, patient P5 expressed concern about the burden of care being primarily with his spousal family caregiver as opposed to other family members. In this context, he did not wish to increase carer burden by communicating his distress to his wife:

It's dealing with that, that side of the family [lack of support] ... I sometimes need now to talk to somebody without [family caregiver].

Pre-existing conflict between patients and family caregivers was also a barrier to supportive relationships. Distress experienced by both patients and caregivers was exacerbated further when patients and caregivers had a history of mutual conflict. Pre-existing conflict was often associated with caregivers feeling forced into a caregiving role. Moreover, pre-existing conflict was an antecedent to caregivers not feeling supported by the person they cared for. Caregiver FCG21 explained:

She [patient] always has been quite a difficult person to live with over the years ... I think she is a selfish person ... a self-oriented person ... She doesn't do praise, she does complaining and I'm going to be told I am doing it [caring] wrong.

In general, tension between patients and family caregivers impeded their ability to engage in challenging conversations surrounding impending death:

I'm [expletive] off with the cancer and she [family caregiver] takes the brunt of it ... She will talk to me [about other things] but talking about death and what's going to happen ... I don't think she wants to be listening to that now. (P15)

We found that deterioration in the patient's health, particularly when it resulted in the need for continuous care from the family caregiver out of concern for patient safety, also impacted adversely on supportive relationships between patients and caregivers. Change in patient health status exacerbated family caregiver distress but also (from the perspective of the family caregiver), limited them to caregiving duties without choice. Caregiver FCG17 recounted:

Because of her head the way it is, the problem is she smokes and does oxygen [home oxygen therapy]. She would pick up the cigarettes ... She would just light up and so there has to be somebody with her all the time. I can't move ... I can't move outside the house or anything.

Deterioration in patients' health was also frustrating for patients themselves, not only heightening their own awareness of their impending death, but also making some patients feel less able to be of support to their family caregiver. Reflecting on his deterioration, patient P15 said:

When I look at myself in the mirror and I was thirteen and a half stone, and I am down to eight and a half stone. I just want to run away from myself and them.

Both patient and family caregiver difficulty in coping with loss of prior roles and routines functioned as a barrier to supportive relationships. Some patients struggled with being a recipient of support if they had previously provided significant levels of support (eg, financial, organisational) to their caregiver, and some caregivers resented the constraints now on them that severely impacted on their own lives. For example, patient P8 (who had been a primary bread winner prior to his illness) and caregiver FCG4 (who cared for her mother in addition to her own family) shared:

She [family caregiver] is over the top ... making sure everything is right which I don't like ... She wants to do everything. She is overprotective ... I keep telling her there is no need for it. (P8)

I miss my own family sometimes, I miss being at [my] home ... But when I do go home, I find myself worrying about my Mam ... It is hard because she can be quiet demanding on me. (FCG4)

Overall, distress associated with bereavement was high for patients and family caregivers. Feelings of loss since the onset of the patient's illness combined with the prospect of having to cope with future loss could make it challenging to decipher how best to support one another:

I think we are grieving already for each other and have been doing for a while. I am sitting there talking to her and [patient] saying "I don't want to be in a box, I don't want to die, I don't want to leave." So, the most difficult contemplating the fact that she's going to die. By a mile that is the most difficult ... us knowing what best to do [for each other]. (FCG11)

DISCUSSION

This study is one of few studies, which aimed from the outset to investigate how mutual support manifests and functions between patients and family caregivers in palliative care.⁹ Findings are further evidence that patients with advanced illness and family caregivers in palliative care have capacity to be mutually supportive. Patients and family caregivers reciprocate in emotional support, but mutual support between patients and family caregivers also involves patients providing emotional support to compensate for other forms of support they feel less able to provide in the context of advanced illness.

Our findings pertaining to what enables and/or restricts supportive relationships between patients and family caregivers in specialist palliative care are new to the field. Research has reported on the importance of support from the wider family to assist family caregivers in their caregiving role.²⁰ However, we have identified that support from the wider family to the

primary caregiver not only benefits the primary caregiver: it also helps foster support between the patient and primary caregiver because patients also encourage the primary caregiver to avail of respite to lessen carer burden.²¹ Our findings expand the evidence on the significance of control for family caregivers in a caregiving role for patients with advanced illness. Research has reported on family caregivers' need to feel in control of the challenges they face in a caregiving role.²² In our study, feeling in control was strongly associated with assuming caregiving responsibilities by choice. Importantly, assuming caregiving duties by choice made family caregivers feel more effective in a supportive role.

Already having had a close relationship prior to the patient illness was a key facilitator of mutual support. However, as reported, some patients and family caregivers had conflict in their relationship with their respective other. Previous studies in palliative care have documented conflict between patients and family caregivers arising from a lack of awareness of and communication about each other's preferences for care²³ but also in the context of family caregivers' need to have some autonomy.²⁴ We found that pre-existing conflict also impacted on the quality of the relationship between patients and family caregivers and was associated with family caregivers feeling restricted in a caregiving role. Indeed, pre-existing conflict was commonly identified in situations when family caregivers felt caregiving was more out of obligation than choice.

Our study adds weight to the evidence that family caregivers who feel competent caring for a patient with specialist palliative care needs have capacity to reassure the person they care for.²⁵ For caregivers in this study, feeling competent was itself bolstered by patients' overt expression of gratitude and support. For family caregivers to feel effective in a caregiving role, they needed support reciprocated by the patient. Conversely, absence of mutual affection between patients and family caregivers made caregiving more difficult for family caregivers.

We observed across the data incidents and patterns of patient and family caregiver distress. Patients and family caregivers in specialist palliative care have reported high levels of distress.^{26 27} In our study, distress was exacerbated by deterioration in the patient's health and lessened by assistance from healthcare professionals. However, we found that overall, it was awareness of mutual loss which explained why patients and family caregivers felt so distressed. Moreover, anticipation of future loss (ie, anticipatory grief) made some participants question their capacity to adequately attend to the needs of their respective other.

In terms of methods and procedures, our study has strengths and limitations. We successfully managed to recruit patients with advanced illness in receipt of

specialist palliative care for a qualitative study during the COVID-19 pandemic, a period in which palliative care research necessitating this type of patient participation was universally challenging to undertake.²⁸ Data were member checked²⁹ and then examined between two investigators to ensure rigour. We have described the setting and participants in detail to enable transferability³⁰ of the findings to similar and different contexts. Many of the participants who agreed to participate in the study had not routinely used General Data Protection Regulation compliant platforms (eg, Zoom, Teams and Webex) and were not readily able to engage with these platforms as a mode for interview. Phone interviews in qualitative research can be as productive as face-to-face interviews.^{31 32} More traditional in-person or video-based online interviews would have allowed for observation of participants in interviews to help further capture and/or contextualise depth of emotion conveyed by them.¹⁹ Our study protocol did not include formal neuropsychological testing of patient participants which if done could have resulted in further contextualisation and explanation of the data. Of note, we did not manage to capture variation in patient diagnoses (beyond variation in cancer diagnoses) ordinarily seen in specialist palliative care and so the findings are contextualised primarily to specialist palliative care in cancer.

Relevance of findings for policy or practice

Our findings have relevance for practice. From the perspective of patients and family caregivers in specialist palliative care, multiple factors both micro (eg, relationships based) and mesolevel (eg, assistance from healthcare professionals) impact on their ability to support one another. However, key was family caregivers needing to have some choice in a caregiving role which was restricted in many cases, by being a primary caregiver to their ill family member. Primary family caregivers in palliative care, by definition, assume most day-to-day caregiving duties.³³ The findings point to the benefit of strategies to help the primary caregiver feel more in control of their situation and have more choice with respect to how they assume a caregiving role. Healthcare professionals need to be cognisant of the need to optimise caregiver autonomy to counterbalance initial caregiver loss in assuming a caregiving role, including helping caregivers process and deal with loss of choice when taking on a caregiver role. Healthcare professionals also have capacity to step in and increase the level of formal support when needed by the caregiver.

Feelings of loss predominated for both patients and family caregivers regardless of the quality of the relationship they reported. The findings warrant addressing the consequences of mutual loss for patients and family caregivers as part of formal care. This could, for example, take the form of patient-family caregiver dyadic interventions focused on relationship

change and adaptation to their own and each other's loss. In addition, educating all members of the health-care team about patient and family caregiver mutual loss including instruction on how to source additional support from the wider family and community to help the patient and family caregiver adapt to their loss, would be beneficial.

Implications for future research

As stated, our findings are limited primarily to the experience of patients and family caregivers in advanced cancer. In addition, while our definition of a family caregiver at the outset of this study extended beyond familial-based relationships, recruitment was limited to either spousal/partner or first-degree relatives. Substantial informal caregiving in palliative care is provided by people beyond spouses, formal partners or blood relatives.³⁴ Further studies in specialist palliative care focused on mutual support between the patient and family caregiver in contexts beyond cancer and which capture heterogeneity in category of family caregiver are needed to both expand on and/or substantiate our findings. Importantly, any future intervention focused on supportive relationships intended to accommodate multiple diagnostic groupings and their family caregivers would need to account for such variation.

CONCLUSION

We have identified and reported key barriers to and facilitators of supportive relationships between patients and family caregivers in specialist palliative care. Some family caregivers did feel constrained in a caregiving role, and mutual loss at times undermined both patient and family caregiver capacity to feel effective in a supportive role. However, external support from both the wider family and healthcare professionals helped both patients and family caregivers cope with advanced illness and could enable supportive relationships between them. The findings are particularly useful for healthcare professionals in specialist palliative care who work closely with both patients and their family caregivers, and where possible members of the wider family, to navigate key challenges associated with loss, including loss of control.

Twitter Rachel McCauley @rachelmccauley, Lucy E Selman @Lucy_Selman and Geraldine Foley @foleyg31

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Contributors GF designed the study and obtained funding as primary investigator to conduct the study. GF supervised the research. RMcCauley engaged directly with gatekeepers, recruited participants, undertook the interviews and analysed the data. GF assisted with interpretation of the data. The final narrative was refined by all authors. KR and RMcQuillan facilitated recruitment and advised on recruitment strategies. GF wrote the manuscript assisted by RMcCauley. KR, RMcQuillan and LES made critical contributions to the

manuscript. All authors reviewed, commented on and approved the final version. GF is the guarantor of this study.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and the study was approved by the Faculty of Health Sciences Research Ethics Committee of Trinity College Dublin (ref 191002) and by the Research Ethics Committee of St. Francis Hospice Dublin (no reference number). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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Appendix B: Patient Invitation Letter



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

Trinity Centre for Health Sciences
School of Medicine
James's Street
Dublin 8

Greetings,

My name is Rachel McCauley and I am a PhD Candidate (PhD student) at Trinity College Dublin. For my PhD I am undertaking a research study focused on how people who use palliative care services and their family caregiver or significant other support one another. The Principal Investigator and supervisor of this study is Dr Geraldine Foley, Assistant Professor, School of Medicine, Trinity College Dublin.

If you decide to participate in the study, it is planned that you and your family caregiver or significant other will be interviewed about your experiences of care and how you feel you both make decisions about care in the interest of each other. You will have the choice to be interviewed alone or together. The interview will take place at a time that is convenient to you both. It is likely that your interview may be conducted through the means of a remote (online) interview.

It is anticipated that your participation in this study will help better understand how people who use palliative care services and their family caregiver or significant other support one another as they engage with services. Understanding how people who use palliative care services and their family caregiver or significant other support one another can help optimise the use and experience of palliative care services for people who access them. Your participation is entirely voluntary, and you can withdraw at any time should you choose to do so.

If you are interested in participating in this study, please feel free to read the attached **Participant Information Leaflet** which explains the study in full and in more detail, and ask me any questions that you might have about the study and I will answer any questions you may have about the study. You may contact me at a time that is convenient to you.

Thank you for your time and consideration.

Kind regards,

A handwritten signature in black ink, appearing to read 'Rachel McCauley'.

Rachel McCauley MSc., BSc. (PhD Candidate)

Email: ramccaul@tcd.ie

Tel: 085 8454872

Appendix C: Family Caregiver Invitation Letter



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

Trinity Centre for Health Sciences

School of Medicine

James's Street

Dublin 8

Greetings,

My name is Rachel McCauley and I am a PhD Candidate (PhD student) at Trinity College Dublin. For my PhD I am undertaking a research study focused on how people who use palliative care services and their family caregiver or significant other support one another. The Principal Investigator and supervisor of this study is Dr Geraldine Foley, Assistant Professor, School of Medicine, Trinity College Dublin.

If you are interested, and you decide to participate in the study, it is planned that you and the person that you care for will be interviewed about your experiences of care and how you feel you both make decisions about care in the interest of each other. You will have the choice to be interviewed alone or together. The interview will take place at a time that is convenient to you both. It is likely that your interview may be conducted through the means of a remote (online) interview.

Your participation in this study will help better understand how people who use palliative care services and their family caregiver or significant other support one another as they engage with services. Understanding how people who use palliative care services and their family caregiver or significant other support one another can help improve the use and experience of palliative care services for people who access them. Your participation is entirely voluntary, and you can withdraw at any time should you choose to do so.

If you are interested in participating in this study, please feel free to read the attached **Participant Information Leaflet** which explains the study in full and in more detail, and ask me any questions that you might have about the study and I will answer any questions you may have about the study. You may contact me at a time that is convenient to you. Sincerest thanks for your time and consideration.

Kind regards,

A handwritten signature in black ink, appearing to read 'R McCauley', with a stylized, cursive script.

Rachel McCauley MSc., BSc. (PhD Candidate)

Email: ramccaul@tcd.ie

Tel: 085 8454872

Appendix D: Participant Information Leaflet (Patient)

Name of Study: Support Exchange between Patients and Family Caregivers in Palliative Care

Site	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s)	Principal Investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin Tel: 01 8963217 Email: foleyg3@tcd.ie Co-Investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin Tel: 085 8454872 Email: ramccaul@tcd.ie
Study Organiser/ Sponsor (if applicable)	Trinity College Dublin
Data Controllers	Trinity College Dublin St. Francis Hospice Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Data Protection Officer St. Francis Hospice Raheny Dublin 5

You are being invited to take part in a research study that is being done in Trinity College Dublin by Dr Geraldine Foley, Assistant Professor, School of Medicine, and by Ms Rachel McCauley, PhD Candidate, School of Medicine. Before you decide whether or not you wish to take part, please read this information sheet carefully. Ask Dr Geraldine Foley (Assistant Professor) and Ms Rachel McCauley, (PhD Candidate) any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or GP.

This leaflet has five main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Future Research

Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study to understand how people who use palliative care services and their family caregiver (or significant other) support one another. The purpose of the study is also to investigate how the relationship between people who use palliative care services and their family caregivers or significant others, impacts on the decisions both make about care.

Why have I been invited to take part?

You have been invited to take part in this study because you are a person that has used palliative care services. The study intends to recruit approximately 25-30 people who have used palliative care services and their family caregiver or significant other.

Do I have to take part? Can I withdraw?

You don't have to take part in this study. It is entirely voluntary. If you decide not to take part, it won't affect your current or future care. You can change your mind about taking part in the study and opt out at any time even if the study has started. If you decide to opt out, it won't affect your current or future care. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Rachel McCauley, PhD Candidate at 085 8454872 or at email ramccaul@tcd.ie who will be able to organise this for you.

What happens if I change my mind?

Your participation is voluntary and you can change your mind by contacting Rachel McCauley, PhD Candidate at 085 8454872 or by email ramccaul@tcd.ie. If you choose not to continue to take part, this will not affect your care in any way. If you choose not to take part any more, you will be asked to fill in a withdrawal form. If you wish, you can ask that any data that has been stored on you to be destroyed. If you request this, we will destroy any data that we have on you except the information that you have shared with us in your interview if we have already analysed that information, or data already used in research studies prior to this time. If we have

not yet analysed the information that you share with us in your interview and you request to withdraw, we will destroy all your data from this study.

How will the study be carried out?

The study will take place between 2020 and 2023 and the study will be conducted by Trinity College Dublin. It is planned that approximately 25-30 people who have used palliative care services and their family caregiver or significant other, will take part. Participants will be interviewed about their experiences of palliative care services and about their preferences for care and decisions about care. Patients and their family caregivers or significant others will also be asked about how the decisions they make are influenced by each other. Patients and their family caregivers or significant others will have a choice to be interviewed together or alone. Due to restrictions arising from COVID-19 and to facilitate adherence to all safety guidelines, it is anticipated that a sizeable proportion of interviews undertaken with participants through the course of this study will be conducted remotely (i.e. online) in real time with audio and/or video. For any interview not conducted remotely, specific location for the interview will be at the discretion of participants.

What will happen to me if I decide to take part?

No part of this research is part of your standard clinical care. If you agree to participate in this study, you will be interviewed by one of the investigators of this study about your experiences of palliative care services. You will be asked about how you and your family caregiver or significant other support one another including when you make decisions about care. You will have the choice to be interviewed alone or be interviewed with your family caregiver or significant other.

The planned interview will last approximately 1 hour or less. Due to restrictions arising from COVID-19 and to facilitate adherence to all safety guidelines, it is likely that your interview will be conducted and recorded remotely (i.e. online) in real time with audio and/or video. You will be advised in detail about the procedures for the online format by Ms Rachel McCauley. You will have the option for your participation in the online interview to be both audio and visual or audio only. Should your participation occur at a time where it is possible to conduct interviews in person (i.e. without the need for online), the interview will be audio recorded only and recorded by an audio recorder. The location for an interview conducted in person, will be where you and/or your family caregiver or significant other feel most comfortable. This may typically be at home.

During the interview you may of course take breaks if you choose to do so and if you feel tired or simply wish for breaks to gather your thoughts. You may stop the interview at any time. It is planned that you will be interviewed on one occasion. The interview will be transcribed (typed up word for word) by Ms Rachel McCauley (PhD Candidate) or by a professional transcriber. A copy of the typed-up interview will be made available to you and you will be asked where possible to check what you have communicated in the interview in order to ensure that you are satisfied with what you have communicated in the interview. If you wish, you may retract anything you said in the interview before the transcript is analysed. You of course may contact the investigators at any time during the study (Contact details of the investigators are on page 1 of this information leaflet). We are aware that the information you provide may at times result in mixed emotional responses about your experiences. Your thoughts and feelings will be fully respected at all times. We will inform you about any additional support services you feel you may require following your participation in the study.

What will happen to my Data?

All data on you in this study will be safely stored by the investigators at Trinity College Dublin in encrypted files on password-accessed computers. All computers used to store and analyse data will be protected by antivirus software. The transcript (typed-up interview) in storage will have no link to your name and it will be labelled/coded with a pseudonym (false name). Personal data stored on you will include your name, contact number, age, gender, diagnosis, time since diagnosis, family support, and the information that you share in your interview. A link between your real name with contact number and your pseudonym will be stored in a separate encrypted file so that your identity remains confidential. The remainder of your personal data will be stored under your pseudonym. Only the investigators of this study will have access to your data for this study. Any data or extract of quotes that may be used in presenting the findings of the study (e.g. publications, reports, and conference presentations) will be labelled with a pseudonym and delineated from any characteristics that could potentially make you identifiable. Your identity will remain confidential at all times. The audio or video recorded interview will be destroyed on completion of the study. Your data including the typed-up interview will be stored for 10 years following completion of the study to allow for maximum dissemination of the findings and if you consent, potential use of the data for future related research. All of your data will then be destroyed by deletion of all electronic-

based data on you. Your signed consent form will be stored in a locked cabinet at Trinity College Dublin until all your data has been destroyed. Your consent form will also be destroyed along with your data. The stored transcript will be pseudonymised whereby any information that could make you identifiable in the transcript will be removed. If you consent to your data being used for future related research, your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. Any pseudonymised data on you will not be used in any future unrelated studies without your explicit consent in the future.

Are there any benefits to taking part in this research?
--

Taking part in this study may not directly benefit you. However, your participation in this research will help us achieve a much better understanding of how people who use palliative care services and their family caregiver or significant other support one another. Evidence so far points to the fact that supportive relationships can have a positive impact in palliative care. Understanding how people who have accessed palliative care services and their family caregivers/significant others support one another is needed to help optimise the use and experience of palliative care services for those who access them.

Are there any risks to me or others if I take part?
--

Whilst it is not possible to totally eliminate the possibility that a connection to your identity could be made, great care will be taken to ensure the confidentiality of all data. The risk to you of a breach of confidentiality is considered very low. Some of the information that you choose to share in your interview may result in mixed emotional responses for you as you talk about your experiences. If you feel in any way upset any time after the interview, the investigators will direct to you to the support/counselling services at St. Francis Hospice or elsewhere as appropriate. In the unlikely event that you are harmed in any way, the researchers on this study are covered by insurance through Trinity College Dublin. This insurance also covers you if you choose to participate in the study.

Will I be told the outcome of the study?

Given the timeframe of the study, it may not be possible to report the findings to all participants. The findings of the study will be reported in reports, academic healthcare journals and disclosed at scientific and healthcare-based conferences. No information which reveals your identity will be disclosed.

Part 2 – Data Protection**What information about me (personal data) will be used as part of this study? Will my medical records be accessed?**

The information that you share in your interview will be used for this study, and may be verified against your medical records, but only information such as your name, contact number, age, gender, diagnosis, time since diagnosis, family support – no sensitive medical information will be accessed. Your data will not be anonymised data but instead pseudonymised data, for which we will have a protected key from which we can link your information back to you if you wish to withdraw it. In addition to what you share with the investigators in your interview, other information that will be used as part of this study include your age, gender, diagnosis, time since diagnosis, and family circumstances/support. Your identity will remain confidential at all times because your real name and contact number and their link to your pseudonym will be stored separately in an encrypted file. The remainder of your personal data will be stored under your pseudonym. Your medical records at St. Francis Hospice may be accessed by the investigators in order to verify information regarding your age, diagnosis, time since your diagnosis, and your family circumstances or support. Your identity will remain confidential at all times.

What will happen to my personal data?

Your personal data will be processed only as is necessary to achieve the objectives of the study. Your data will not be processed in a way that could cause damage or stress to you. Your personal data will be stored in pseudonymised form (as described in Part 1 of this information leaflet) for up to 10 years after the study to allow for maximum dissemination of the research and so that your data can be available to be used for future related research if you give consent that your data can be used for future related research. If you give consent that your data can be used for future related research, the pseudonymised transcript and your other

pseudonymised personal data will not leave the State. Your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. All of your data will be destroyed following the 10-year period after the study by deletion of all electronic storage of your data. Your signed consent form will be stored in a locked cabinet at Trinity College Dublin until your data has been destroyed. Your consent form will also be destroyed along with your data.

The data controllers of this study are Trinity College Dublin and St. Francis Hospice Dublin. The investigators of this study may use a professional transcription service to transcribe your interview (Audiotrans Ltd, Tel: 01 4520555, Email: info@audiotrans.ie, Address: Unit 8 Fashion City, Ballymount, Dublin 24). If used, Audiotrans Ltd will be a data processor for this study.

Who will access and use my personal data as part of this study?
--

Only the investigators of this study will have access to your data. The investigators include the following:

Principal investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin.

Co-investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin.

Your medical records at St. Francis Hospice may be accessed by the investigators in order to verify information about your age, diagnosis, time since your diagnosis, and your family circumstances or support.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we will do this:

- All computers used to store and analyse your data will be protected by antivirus software. All computers will be password-accessed.
- All electronic files that store and analyse your data will be password-encrypted.
- Your transcript (typed-up interview) in storage will have no link to your name and it will be labelled with a pseudonym (false name). The link between your real name and your

pseudonym will be stored in a separate encrypted file so that your identity remains confidential.

- Only the investigators of this study will have access to your data.
- Any data or extract of quotes that may be used in presenting the findings of the study (e.g. publications, reports, and conference presentations) will be labelled with your pseudonym and delineated from any characteristics that could potentially make you identifiable.
- Your signed consent form will be stored securely in a locked cabinet at Trinity College Dublin and destroyed once all your data has been destroyed.
- A Risk Assessment of the data protection implications of the health research and/or a Data Protection Impact Assessment was carried out and an indication of the level of risk identified as low.
- The researchers carrying out the research who have access to personal data are bound by a professional code of secrecy (like doctors) or a contractual code of secrecy (that would mean disciplinary action for employees who disclosed or facilitated unauthorised access to the personal data).
- Training in data protection law and practice has been provided to those individuals involved in carrying out the research.

What is the lawful basis to use my personal data?
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By law, based on the European General Data Protection Regulation (GDPR), Articles 6 and 9, we can use your personal information for scientific research and in the public interest. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted

- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie (Website: www.tcd.ie/privacy) or St. Francis Hospice Dublin: Data Protection Officer, St. Francis Hospice, Raheny, Dublin 5. Email: dataprotection@sfh.ie

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin on [date] and by St. Francis Hospice Research Ethics Committee on [date]. The Principal Investigator of this study (Dr Geraldine Foley) is a committee member and vice-chairperson of the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin. Contact details for committees are the following:

- Secretary
Faculty of Health Sciences Research Ethics Committee
Chemistry Building
Trinity College Dublin
Dublin 2
Email: ethicscommittee@tcd.ie

- Secretary
St. Francis Hospice Research Ethics Committee
Station Road
Raheny
Dublin 5
Email: info@sfh.ie

The investigators will comply with all reporting agreements to each committee including final reports to each committee on completion of the study.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is being done by Dr Geraldine Foley, Assistant Professor, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin and by Ms Rachel McCauley, PhD Candidate, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin. Ms Rachel McCauley is undertaking this study for the purpose of obtaining a research doctoral degree (PhD) at Trinity College Dublin. The research is funded by Trinity College Dublin under the Trinity College Dublin Provost's PhD Project Awards. The Trinity College Dublin Provost's PhD Project

Award is a fully-funded PhD Scholarship for Ms Rachel McCauley (PhD Candidate). The findings of the study will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, participants will not be paid for taking part in this study and there is no financial cost to participating in this study.

Part 4 – Future Research

Will my personal data be used in future studies?

The investigators of this study will ask you whether you consent or not for use of your data in future studies related to support exchange between patients and family caregivers in palliative care. It is possible that the information that you share about your experiences can be used to aid future research that will continue to better our understanding of how people engage with palliative care services. If you consent to your data being used for future related research, your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. Any future research will only take place if the future research has ethical approval.

Participating in the current study means that you have only given permission for your data to be used for the current study and the investigators are seeking permission to store your data for possible future use in research. Your participation is voluntary and you can withdraw your consent to future research at any time.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

Principal Investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin

Tel: 01 8963217

Email: foleyg3@tcd.ie

Co-Investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin

Tel: 085 8454872

Email: ramccaul@tcd.ie

Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Data Protection Officer, St. Francis Hospice Dublin: Data Protection Officer, St. Francis Hospice, Raheny, Dublin 5. Email: dataprotection@sfh.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

Soon after the interview you will be provided if you wish, with a transcript of your interview and asked by the investigators to check that you are satisfied with your transcript. If you agree to your personal data being used for future research and want to be consented at the time of that future research, the investigators will contact you. If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Appendix E: Participant Information Leaflet (Caregiver)



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



Site	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s)	Principal Investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin Tel: 01 8963217 Email: foleyg3@tcd.ie Co-Investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin Tel: 085 8454872 Email: ramccaul@tcd.ie
Study Organiser/ Sponsor (if applicable)	Trinity College Dublin
Data Controllers	Trinity College Dublin St. Francis Hospice Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Data Protection Officer St. Francis Hospice

	Raheny Dublin 5
Name of Study:	Support Exchange between Patients and Family Caregivers in Palliative Care



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



You are being invited to take part in a research study that is being done in Trinity College Dublin by Dr Geraldine Foley, Assistant Professor, School of Medicine, and by Ms Rachel McCauley, PhD Candidate, School of Medicine. Before you decide whether or not you wish to take part, please read this information sheet carefully. Ask Dr Geraldine Foley (Assistant Professor) and Ms Rachel McCauley, (PhD Candidate) any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or GP.

This leaflet has five main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Future Research

Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study to understand how people who use palliative care services and their family caregiver (or significant other) support one another. The purpose of the study is also to investigate how the relationship between people who use palliative care services and their family caregivers or significant others, impacts on the decisions both make about care.

Why have I been invited to take part?

You have been invited to take part in this study because you are a family caregiver or significant other of a person that has used palliative care services. The study intends to recruit approximately 25-30 people who have used palliative care services and their family caregiver or significant other.

Do I have to take part? Can I withdraw?

You don't have to take part in this study. It is entirely voluntary. If you decide not to take part, it won't affect current or future care of the person whom you care for, or any care that you may access as a family caregiver or significant other to the person you care for. You can change your mind about taking part in the study and opt out at any time even if the study has started. If you decide to opt out, it won't affect current or future care of the person whom you care for, or any care that you may access as a family caregiver or significant other to the person you care for. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Rachel McCauley, PhD Candidate at 085 8454872 or at email ramccaul@tcd.ie who will be able to organise this for you.

What happens if I change my mind?

Your participation is voluntary and you can change your mind by contacting Rachel McCauley, PhD Candidate at 085 8454872 or by email ramccaul@tcd.ie. If you choose not to continue to take part, this will not affect current or future care of the person whom you care for, or any care that you may access as a family caregiver or significant other to the person you care for. If you

choose not to take part any more, you will be asked to fill in a withdrawal form. If you wish, you can ask that any data that has been stored on you to be destroyed. If you request this, we will destroy any data that we have on you except the information that you have shared with us in your interview if we have already analysed that information, or data already used in research studies prior to this time. If we have not yet analysed the information that you share with us in your interview and you request to withdraw, we will destroy all your data from this study.

How will the study be carried out?

The study will take place between 2020 and 2023 and the study will be conducted by Trinity College Dublin. It is planned that approximately 25-30 people who have used palliative care services and their family caregiver or significant other, will take part. Participants will be interviewed about their experiences of palliative care services and about their preferences for care and decisions about care. Patients and their family caregivers or significant others will also be asked about how the decisions they make are influenced by each other. Patients and their family caregivers or significant others will have a choice to be interviewed together or alone. Due to restrictions arising from COVID-19 and to facilitate adherence to all safety guidelines, it is anticipated that a sizeable proportion of interviews undertaken with participants through the course of this study will be conducted remotely (i.e. online) in real time with audio and/or video. For any interview not conducted remotely, specific location for the interview will be at the discretion of participants.

What will happen to me if I decide to take part?

No part of this research is part of standard clinical care that you or the person that you care for may receive. If you agree to participate in this study, you will be interviewed by one of the investigators of this study about your experiences of palliative care services. You will be asked about how you and the person that you care for support one another including when you make decisions about care. You will have the choice to be interviewed alone or be interviewed with the person that you care for.

The planned interview will last approximately 1 hour or less. Due to restrictions arising from

COVID-19 and to facilitate adherence to all safety guidelines, it is likely that your interview will be conducted and recorded remotely (i.e. online) in real time and with audio and/or video. You will be advised in detail about the procedures for the online format by Ms Rachel McCauley. You will have the option for your participation in the online interview to be both audio and visual or audio only. Should your participation occur at a time where it is possible to conduct interviews in person (i.e. without the need for online), the interview will be audio recorded only and recorded by an audio recorder. The location for an interview conducted in person will be where you and the person that you care for feel most comfortable. This may typically be at home.

During the interview you may of course take breaks if you choose to do so and if you feel tired or simply wish for breaks to gather your thoughts. You may stop the interview at any time. It is planned that you will be interviewed on one occasion. The interview will be transcribed (typed up word for word) by Ms Rachel McCauley (PhD Candidate) or by a professional transcriber. A copy of the typed-up interview will be made available to you and you will be asked where possible to check what you have communicated in the interview in order to ensure that you are satisfied with what you have communicated in the interview. If you wish, you may retract anything you said in the interview before the transcript is analysed. You of course may contact the investigators at any time during the study (contact details of the investigators are on page 1 of this information leaflet). We are aware that the information you provide may at times result in mixed emotional responses. Your thoughts and feelings will be fully respected at all times. We will inform you about any additional support services you feel you may require following your participation in the study.

What will happen to my Data?

All data on you in this study will be safely stored by the investigators at Trinity College Dublin in encrypted files on password-accessed computers. All computers used to store and analyse data will be protected by antivirus software. The transcript (typed-up interview) in storage will have no link to your name and it will be labelled/coded with a pseudonym (false name). Personal data stored on you will include your name, contact number, age, gender, family circumstances/support, and the information that you share in your interview. A link between your real name with contact number and your pseudonym will be stored in a separate encrypted file so that your identity remains confidential. The remainder of your personal data

will be stored under your pseudonym. Only the investigators of this study will have access to your data for this study. Any data or extract of quotes that may be used in presenting the findings of the study (e.g. publications, reports, and conference presentations) will be labelled with a pseudonym and delineated from any characteristics that could potentially make you identifiable. Your identity will remain confidential at all times. The audio or video recorded interview will be destroyed on completion of the study. Your data including the typed-up interview will be stored for 10 years following completion of the study to allow for maximum dissemination of the findings and if you consent, potential use of the data for future related research. All of your data will then be destroyed by deletion of all electronic-based data on you. Your signed consent form will be stored in a locked cabinet at Trinity College Dublin until all your data has been destroyed. Your consent form will also be destroyed along with your data. The stored transcript will be pseudonymised whereby any information that could make you identifiable in the transcript will be removed. If you consent to your data being used for future related research, your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. Any pseudonymised data that is retained on you will not be used in any future unrelated studies without your explicit consent being obtained.

Are there any benefits to taking part in this research?
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Taking part in this study may not directly benefit you or the person who you care for. However, your participation in this research will help us achieve a much better understanding of how people who use palliative care services and their family caregiver or significant other support one another. Evidence so far points to the fact that supportive relationships can have a positive impact in palliative care. Understanding how people who have accessed palliative care services and their family caregivers/significant others support one another is needed to help optimise the use and experience of palliative care services for those who access them.

Are there any risks to me or others if I take part?
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Whilst it is not possible to totally eliminate the possibility that a connection to your identity could be made, great care will be taken to ensure the confidentiality of all data. The risk to you of a

breach of confidentiality is considered very low. Some of the information that you choose to share in your interview may result in mixed emotional responses for you as you talk about your experiences. If you feel in any way upset any time after the interview, the investigators will direct to you to the support/counselling services at St. Francis Hospice or elsewhere as appropriate. In the unlikely event that you are harmed in any way, the researchers on this study are covered by insurance through Trinity College Dublin. This insurance also covers you if you choose to participate in the study.

Will I be told the outcome of the study?

Given the timeframe of the study, it may not be possible to report the findings to all participants. The findings of the study will be reported in reports, academic healthcare journals and disclosed at scientific and healthcare-based conferences. No information which reveals your identity will be disclosed.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

The information that you share in your interview will be used for this study. Your data will not be anonymised data but instead pseudonymised data because your data can be tracked back to you. In addition to what you share with the investigators in your interview, other information that will be used as part of this study include your age, gender, and family circumstances/support. Your identity will remain confidential at all times because your real name and contact number and their link to your pseudonym will be stored separately in an encrypted file. The remainder of your personal data will be stored under your pseudonym. Your own medical records will not be accessed.

What will happen to my personal data?

Your personal data will be processed only as is necessary to achieve the objectives of the study. Your data will not be processed in a way that could cause damage or stress to you. Your personal data will be stored in pseudonymised form (as described in Part 1 of this information

leaflet) for up to 10 years after the study to allow for maximum dissemination of the research and so that your data can be available to be used for future related research if you give consent that your data can be used for future related research. If you give consent that your data can be used for future related research, the pseudonymised transcript and your other pseudonymised personal data will not leave the State. Your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. All of your data will be destroyed following the 10-year period after the study by deletion of all electronic storage of your data. Your signed consent form will be stored in a locked cabinet at Trinity College Dublin until your data has been destroyed. Your consent form will also be destroyed along with your data.

The data controllers of this study are Trinity College Dublin and St. Francis Hospice Dublin. The investigators of this study may use a professional transcription service to transcribe your interview (Audiotrans Ltd, Tel: 01 4520555, Email: info@audiotrans.ie, Address: Unit 8 Fashion City, Ballymount, Dublin 24). If used, Audiotrans Ltd will be a data processor for this study.

Who will access and use my personal data as part of this study?
--

Only the investigators of this study will have access to your data. The investigators include the following:

Principal investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin.

Co-investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we will do this:

- All computers used to store and analyse your data will be protected by antivirus software. All computers will be password-accessed.

- All electronic files that store and analyse your data will be password-encrypted.
- Your transcript (typed-up interview) in storage will have no link to your name and it will be labelled with a pseudonym (false name). The link between your real name and your pseudonym will be stored in a separate encrypted file so that your identity remains confidential.
- Only the investigators of this study will have access to your data.
- Any data or extract of quotes that may be used in presenting the findings of the study (e.g. publications, reports, and conference presentations) will be labelled with your pseudonym and delineated from any characteristics that could potentially make you identifiable.
- Your signed consent form will be stored securely in a locked cabinet at Trinity College Dublin and destroyed once all your data has been destroyed.
- A Risk Assessment of the data protection implications of the health research and/or a Data Protection Impact Assessment was carried out and an indication of the level of risk identified as low.
- The researchers carrying out the research who have access to personal data are bound by a professional code of secrecy (like doctors) or a contractual code of secrecy (that would mean disciplinary action for employees who disclosed or facilitated unauthorised access to the personal data).
- Training in data protection law and practice has been provided to those individuals involved in carrying out the research.

What is the lawful basis to use my personal data?

By law, based on the European General Data Protection Regulation (GDPR), Articles 6 and 9, we can use your personal information for scientific research and in the public interest. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie (Website: www.tcd.ie/privacy) or St. Francis Hospice Dublin: Data Protection Officer, St. Francis Hospice, Raheny, Dublin 5. Email: dataprotection@sfh.ie

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin on [date] and by St. Francis Hospice Research Ethics Committee on [date]. The Principal Investigator of this study (Dr Geraldine Foley) is a committee member and vice-chairperson of the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin. Contact details for committees are the following:

- Secretary
Faculty of Health Sciences Research Ethics Committee
Chemistry Building, Trinity College Dublin, Dublin 2
Email: ethicscommittee@tcd.ie

- Secretary
St. Francis Hospice Research Ethics Committee
Station Road, Raheny, Dublin 5
Email: info@sfh.ie

The investigators will comply with all reporting agreements to each committee including final reports to each committee on completion of the study.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is being done by Dr Geraldine Foley, Assistant Professor, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin and by Ms Rachel McCauley, PhD Candidate, Discipline of Occupational Therapy, School of Medicine, Trinity College Dublin. Ms Rachel McCauley is undertaking this study for the purpose of obtaining a research doctoral degree (PhD) at Trinity College Dublin. The research is funded by Trinity College Dublin under the Trinity College Dublin Provost's PhD Project Awards. The Trinity College Dublin Provost's PhD Project Award is a fully-funded PhD Scholarship for Ms Rachel McCauley (PhD Candidate). The findings of the study will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, participants will not be paid for taking part in this study and there is no financial cost to participating in this study.

Part 4 – Future Research

Will my personal data be used in future studies?

The investigators of this study will ask you whether you consent or not for use of your data in future studies related to support exchange between patients and family caregivers in palliative care. It is possible that the information that you share about your experiences can be used to aid future research that will continue to better our understanding of how people engage with palliative care services. If you consent to your data being used for future related research, your pseudonymised data will be used only by the investigators for future related studies. Your data will remain only with the investigators. Any future research will only take place if the future research has ethical approval.

Participating in the current study means that you have only given permission for your data to be used for the current study and the investigators are seeking permission to store your data for possible future use in research. Your participation is voluntary and you can withdraw your consent to future research at any time.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

Principal Investigator: Dr Geraldine Foley, Assistant Professor in Occupational Therapy, School of Medicine, Trinity College Dublin

Tel: 01 8963217

Email: foleyg3@tcd.ie

Co-Investigator: Ms Rachel McCauley, PhD Candidate, School of Medicine, Trinity College Dublin

Tel: 085 8454872

Email: ramccaul@tcd.ie

Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Data Protection Officer, St. Francis Hospice Dublin: Data Protection Officer, St. Francis Hospice, Raheny, Dublin 5. Email: dataprotection@sfh.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

Soon after the interview you will be provided if you wish, with a transcript of your interview and asked by the investigators to check that you are satisfied with your transcript. If you agree to your personal data being used for future research and want to be consented at the time of that future research, the investigators will contact you. If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Appendix F: Patient Consent Form



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

Patient Consent Form

Study Name: Support Exchange between Patients and Family Caregivers in Palliative Care

There are 25 sections in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements.
Thank you for participating.

Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary , and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect my future medical care.	
I understand that my medical notes and records at St. Francis Hospice may be looked at by the investigators of this study where it is relevant to the research. I agree that these individuals can access my records in order to verify information such as age, gender, diagnosis, time since diagnosis, family support. I understand that all information will be kept private and confidential and that my name will not be disclosed.	

I understand that I will be interviewed by one of the investigators for no longer than an hour about my experiences of palliative care services and about how I and my family caregiver or significant other support one another. I understand that the interview will be conducted remotely (i.e. online) in real time when it is not possible to conduct the interview in person. I understand that I have the option for my participation in the online interview to be both audio and visual or audio only.	
I understand that I will have a choice to be interviewed alone or with my family caregiver or significant other. For any interview conducted in person, the location of an interview will be where is convenient to me and/or my family caregiver or significant other.	
I understand that I may take breaks in the interview if I need to or stop the interview at any time.	
I understand that my interview will be audio and/or video recorded. I understand that my interview recording will be stored safely at Trinity College Dublin and that it will be destroyed when the study is completed.	
I understand that the interview will be transcribed and that I will be given a copy of the typed-up interview so that I can check that I am satisfied with the interview.	
I understand that I can retract anything that I said in the interview before the transcript is analysed by the investigators.	

I understand that I can ask for all my data to be destroyed if I choose to withdraw from the study except where my interview data has already been analysed by the investigators.	
I understand that the transcript will be stored securely for 10 years following completion of the study along with my consent form. I understand that the transcript in storage will be pseudonymised which means removal of information that could make me identifiable. I understand that all my data and my consent form will then be destroyed.	
I understand that any pseudonymised data that is retained on me after the study will not be used in any future unrelated studies without my explicit consent being obtained.	
I understand that I will be informed by the investigators about any additional support services I feel I may require following my participation in the study.	
I understand that I will not be paid for taking part in this study.	
I know how to contact the research team if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by phone as part of this research study.	
Data processing	Tick box

I understand that the investigators of this study will only have access to my data for this study except in the case where my interview data has been transcribed by a professional transcriber.	
I understand that personal information about me will not be shared with third parties except for a professional transcription service if my interview is transcribed by a professional transcription service and not by the investigators, as described in the Information leaflet. I understand that my data will not be shared with any other investigators.	
I understand that personal information about me will be protected in accordance with the General Data Protection Regulation.	
I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information may not be given to me.	
I understand that I can stop taking part in this study at any time without giving a reason and this will not affect my future medical care.	

FUTURE USE OF INFORMATION		
RETENTION OF RESEARCH SAMPLES IN THE FUTURE	Y	N
OPTION 1: I give permission for my personal information to be stored for <u>possible future research related</u> to the current study in the area of palliative care <u>only if consent is obtained</u> at the time of the future research and the research is approved by a Research Ethics Committee.		
OPTION 2: I give permission for my personal information to be stored for <u>possible future research related</u> to the current study in the area of palliative care <u>without further consent</u> being required but only if the research is approved by a Research Ethics Committee.		

OPTION 3: I understand <u>I will not be paid for any</u> future use of my personal information or products derived from it.		
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Participant Name (Block Capitals) Participant Signature Date

Witness Name (Block Capitals) Witness Signature Date

Statement of Investigator's responsibility:

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

Rachel McCauley BSc., MSc. (PhD Candidate)

Signature: _____

Date: _____

Contact details: _____

Appendix G: Family Caregiver Consent Form



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

Caregiver Consent Form

Study Name: Support Exchange between Patients and Family Caregivers in Palliative Care

There are 24 sections in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask any questions you may have when reading each of the statements.

Thank you for participating.

Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary , and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect my relative's future medical care.	

I understand that I will be interviewed by one of the investigators for no longer than an hour about my experiences of palliative care services and about how I and my relative support one another. I understand that the interview will be conducted remotely (i.e. online) in real time when it is not possible to conduct the interview in person. I understand that I have the option for my participation in the online interview to be both audio and visual or audio only.	
I understand that I will have a choice to be interviewed alone or with my relative. For any interview conducted in person, the location of the interview will be where is convenient to me and/or my relative.	
I understand that I may take breaks in the interview if I need to or stop the interview at any time.	
I understand that my interview will be audio and/or video recorded. I understand that my interview recording will be stored safely at Trinity College Dublin and that it will be destroyed when the study is completed.	
I understand that the interview will be transcribed and that I will be given a copy of the typed-up interview so that I can check that I am satisfied with the interview.	
I understand that I can retract anything that I said in the interview before the transcript is analysed by the investigators.	
I understand that I can ask for all my data to be destroyed if I choose to withdraw from the study except where my interview data has already been analysed by the investigators.	

I understand that the transcript will be stored securely for 10 years following completion of the study along with my consent form. I understand that the transcript in storage will be pseudonymised which means removal of information that could make me identifiable. I understand that all my data and my consent form will then be destroyed.	
I understand that any pseudonymised data that is retained on me after the study will not be used in any future unrelated studies without my explicit consent being obtained.	
I understand that I will be informed by the investigators about any additional support services I feel I may require following my participation in the study.	
I understand that I will not be paid for taking part in this study.	
I know how to contact the research team if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by phone as part of this research study.	
Data processing	Tick box

I understand that the investigators of this study will only have access to my data for this study except in the case where my interview data has been transcribed by a professional transcriber.	
I understand that personal information about me will not be shared with third parties except for a professional transcription service if my interview is transcribed by a professional transcription service and not by the investigators, as described in the Information leaflet. I understand that my data will not be shared with any other investigators.	
I understand that personal information about me will be protected in accordance with the General Data Protection Regulation.	
I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information may not be given to me.	
I understand that I can stop taking part in this study at any time without giving a reason and this will not affect my relative's future medical care.	

FUTURE USE OF INFORMATION		
RETENTION OF RESEARCH SAMPLES IN THE FUTURE	Y	N
OPTION 1: I give permission for my personal information to be stored for <u>possible future research related</u> to the current study in the area of palliative care <u>only if consent is obtained</u> at the time of the future research and the research is approved by a Research Ethics Committee.		
OPTION 2: I give permission for my personal information to be stored for <u>possible future research related</u> to the current study in the area of palliative care <u>without further consent</u> being required but only if the research is approved by a Research Ethics Committee.		
OPTION 3: I understand <u>I will not be paid for any</u> future use of my personal information or products derived from it.		

-----	-----	-----
Participant Name (Block Capitals)	Participant Signature	Date
-----	-----	-----
Witness Name (Block Capitals)	Witness Signature	Date

Statement of Investigator's responsibility:

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

Rachel McCauley BSc., MSc. (PhD Candidate)

Signature: _____

Date: _____

Contact details: _____

Appendix H: Ethical Approval Letters

Original Applications: January 2020



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

Ms Rachel McCauley
Trinity Centre for Health Sciences,
James's Street,
Dublin 8

17th January 2020

Ref: 191002

Title of Study: Support Exchange between Patients and Family Caregivers in Palliative Care.

Dear Rachel,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in October. We are pleased to inform you that the above project has ethical approval to proceed.

This study has been ethically approved. We would advise you to seek review and comments on your DPIA from the DPO if required prior to study commencement'

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Prof. Jacintha O'Sullivan'.

Prof. Jacintha O'Sullivan
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie



St. Francis Hospice Dublin

(Under the care of the Daughters of Charity of St. Vincent de Paul)

ST. FRANCIS HOSPICE RAHENY, STATION ROAD, RAHENY, DUBLIN 5, D05 E392. TELEPHONE (01) 832 7535 FAX: (01) 832 7635
ST. FRANCIS HOSPICE BLANCHARDSTOWN, BLANCHARDSTOWN, DUBLIN 15, D15 DE98. TELEPHONE: (01) 829 4000 FAX: (01) 829 4099
E-MAIL: info@sfh.ie WEBSITE: www.sfh.ie

Ms Rachel McCauley
PhD Student
Trinity Centre for Health Sciences
James's Street
Dublin 8

7th January, 2020

Dear Rachel

RE: "Support exchange between patients and family caregivers in palliative care"
Principal Investigator: Rachel McCauley

I wish to acknowledge with thanks receipt of required amendments to the above study. In this regard I wish to advise that these amendments have been considered and approved.

Yours sincerely

Tom McMahon
Chairperson
Research Ethics Committee

Directors: Mr. Dermot McCarthy (Chairman), Mr. Tom McMahon, Prof. Peter Daly, Ms. Mary Hayes,
Sr. Bernadette MacMahon, Sr. Claire McKiernan, Mr. James Flynn, Dr. Carol-Ann Casey,
Mr. Patrick Kenny, Sr. Nuala Dolan, Mr. Joseph Pitcher, Fr. Philip Baxter, Mr. Padraig O'Dea.



Registered Charity No. 20027193

Company Registration No. 153874

Charitable Tax Exemption No. CHY 10568

St Francis Hospice Dublin is a Company Limited by Guarantee.

Registered Office: St Francis Hospice Raheny, Station Road, Raheny, Dublin 5, D05 E392, Ireland.

Amended Applications: September/October 2020



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

Rachel McCauley,
Discipline of Occupational Therapy
Trinity Centre for Health Sciences,
James's Street,
Dublin 8

29th September 2020

Ref: 191002

Title of Study: Support Exchange between Patients and Family Caregivers in Palliative Care

Dear Rachel,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in September 2020.

Ethical approval for this project is granted subject to concurrent approval by St. Francis Research Ethics Committee.

A copy of St. Francis Research Ethics Research Committee approval must be with the FHS Research Ethics Committee before the study may begin in Trinity.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Jacintha O'Sullivan
Chairperson
Faculty Research Ethics Committee

Dámh na nEalaíochtaí Stáinte
Foirgneamh na Céimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie



(Under the care of the Daughters of Charity of St. Vincent de Paul)

ST. FRANCIS HOSPICE RAHENY, STATION ROAD, RAHENY, DUBLIN 5, D05 E392. TELEPHONE (01) 832 7535 FAX: (01) 832 7635
ST. FRANCIS HOSPICE BLANCHARDSTOWN, BLANCHARDSTOWN, DUBLIN 15, D15 DE98. TELEPHONE: (01) 829 4000 FAX: (01) 829 4099
E-MAIL: info@sfh.ie WEBSITE: www.sfh.ie

Ms. Rachel McCauley
Trinity Centre for Health Sciences
James's Street
Dublin 8

22nd October, 2020.

Dear Rachel

RE: **"Support exchange between patients and family caregivers in palliative care"**
Principal Investigator: Rachel McCauley

I refer to your amendments to the above research which were considered by the Research Ethics Committee at its meeting on 21st October, 2020.

As Chairperson of the Committee, I am pleased to advise that these amendments have been approved by the Research Ethics Committee.

Yours sincerely

Tom McMahon
Chairperson
Research Ethics Committee

Directors: Mr. Dermot McCarthy (Chairman), Mr. Tom McMahon, Prof. Peter Daly, Ms. Mary Hayes, Sr. Bernadette MacMahon, Sr. Claire McKiernan, Mr. James Flynn, Dr. Carol-Ann Casey, Mr. Patrick Kenny, Sr. Nuala Dolan, Mr. Joseph Pitcher, Mr. Pdraig O'Dea, Fr. Peter Rodgers.

Registered Charity No. 20027193

Company Registration No. 153874

Charitable Tax Exemption No. CHY 10568

Appendix I: Interview Guide (Patient)

- What are your experiences so far of palliative care with [family caregiver]?
- How do you think both of you are coping?
- What do you think is the best kind of help or support to get from [family caregiver]? What makes it difficult or easy to accept support from [family caregiver]?
- How would you describe the way you rely (or might not rely) on [family caregiver]?
- In what way(s) do you feel you are a support (or not) to [family caregiver]?
- What do you think is the best kind of help or support that you give or can give to [family caregiver]?
- How might what you want for your care (e.g., medical treatments, multi-disciplinary care, home-based care, psychological support) be influenced by what you think is best for [family caregiver]?
- When you think about making decisions about your care (e.g. medical treatments, multi-disciplinary care, home-based care, psychological support), in what way have you made/do you make decisions with [family caregiver]? (If you make/made decisions independent of [family caregiver], why do think that is/was?)
- How might your responsibility to [family caregiver] impact your preferences for care and how you decide about your care?

- Is there anything else you would like to say that you have not had an opportunity to say?

Appendix J: Interview Guide (Family Caregiver)

- What are your experiences so far of palliative care with [patient]?
- How do you think both of you are coping?
- In what way(s) do you feel you are a support (or not) to [patient]?
- What do you think is the best kind of help or support that you give or can give to [patient]? What makes it difficult or easy to provide help to [patient]?
- What do you think is the best kind of help or support that [patient] provides or can provide to you?
- How would you describe the way you rely (or might not rely) on [patient]?
- How might what you want for [patient's] care (e.g., medical treatments, multi-disciplinary care, home-based care, psychological support) and for your own care (e.g., any type of help), be influenced by what you think is best for [patient]?
- When you think about decision-making for [patient's] care (e.g. medical treatments, multi-disciplinary care, home-based care, psychological support) and your own care, in what way have you made/do you make decisions with [patient]? (If you feel that you are not/have not been making decisions with [patient], why do think that is/was?)
- How might your responsibility to [patient] impact your preferences for care?
- Is there anything else you would like to say that you have not had an opportunity to say?

Appendix K: Interview Guide (Patient and Family Caregiver Interviewed Together)

- **(P & FG)** What are your experiences so far of palliative care (together)?
- **(P & FG)** How do you think both of you are coping?
- **(P & FG)** In what way do you feel you are a support (or not) to each other?
- **(P)** What do you think is the best kind of help or support to get from [family caregiver]? What makes it difficult or easy to accept support from [family caregiver]?
(FG) What do you think is the best kind of help or support that [patient] provides or can provide to you?
- **(P)** What do you think is the best kind of help or support that you give or can give to [family caregiver]?
(FG) What do you think is the best kind of help or support that you give or can give to [patient]? What makes it difficult or easy to provide help to [patient]?
- **(P)** How would you describe the way you rely (or might not rely) on [family caregiver]?
(FG) How would you describe the way you rely (or might not rely) on [patient]?
- **(P)** How might what you want for your care (e.g., medical treatments, multi-disciplinary care, home-based care, psychological support) be influenced by what you think is best for [family caregiver]?
(FG) How might what you want for [patient's] care (e.g., medical treatments, multi-disciplinary care, home-based care, psychological support) and for your own care (e.g., any type of help), be influenced by what you think is best for [patient]?

- **(P & FG)** When you think about making decisions about care (e.g. medical treatments, multi-disciplinary care, home-based care, psychological support), in what way have you made/do you make decisions together? (If you do/did not make decisions together, why do think that is/was?)

- **(P)** How might your responsibility to [family caregiver] impact your preferences for care and how you decide about your care?
(FG) How might your responsibility to [patient] impact your preferences for care?

- **(P & FG)** Is there anything else you would like to say that you have not had an opportunity to say?

Appendix L: Sample Memo

Memo recorded during and post-interview with FCG8 – Tina.

Observations	Codes
• Change in patient's personality as a result of diagnosis – re-priorisation of family at highest priority • Shock at diagnosis – exacerbated by delivery of news over phone. Family separate when received news. • New articulation of affection and appreciation by patient – appreciated by FCG – easier to provide care? • Respite – time away from patient or formal psychosocial support more beneficial? Both? • Respite needed more in earlier stages of caregiving – does FCG become more able to cope over time or is this as a result of patient's increased emotional disclosure/expressions of appreciation? • Dependent on older daughter for support. Support appears to be more beneficial from children when children are adults, fully privy to full picture – is this age related or related to family dynamics/closeness. • Desire to socialise with friends – friend support needed in addition to familial	• New roles • Family dynamics – increased cohesion • Physical presence • Expressions of love as a form of patient support to FCGs • Facilitators of mutual support – momentum of mutual support • Respite • Respite • Time apart • Facilitator of mutual support • Familial support • Open disclosure in family • Respite

support? Degree of separation needed? • Patience – FCG needs more patience than the patient in her view. More allowances made for patient. • Personal choice here vs obligation but respite is needed. • FCG appreciating patient's new affection but makes the anticipatory grief more difficult. • Need for male perspective on spousal caregiving at this life stage (i.e. with adult children)	• Personality change in patient • Inequitable relationship • Making allowances • Personal responsibility • Personality change in patient
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Appendix M: Sample Transcript

Transcript of interview with patient Louise (P6) and her family caregiver Kelly (FCG6).

Participants' names and all other names mentioned in this transcript are pseudonyms.

Researcher (R): Perfect. So Louise and Kelly, I'm recording now, are you okay to start?

Louise (P): Yeah.

Kelly (FCG): *Yeah.*

R: Perfect. That's great. Thank you so much. Um, so firstly, would you be able to just tell me your ages and your relationship to each other?

P: Right, I'm 57 and Kelly is my daughter.

R: Great.

FCG: *I'm Kelly. And I'm 26. And that's my mam.*

R: Great. Thank you so much. And so would you be able to just tell me, and you can both give it a different response to this. Just a bit about your kind of story in accessing palliative care services and your experience of the services so far.

P: Well I'm not in it that long but I have to say they're very helpful. They ring me all the time and if I want anything, I can just pick up the phone, to ring them. So yeah they're very very good now the nurses are great coming out. Going to get into the nitty gritty now but I'd say when the time comes now, I'll probably move to the hospice. But I heard it's fantastic.

R: To become an inpatient in there is it?

P: Yeah, I've already kind of decided that when things get really bad could I go in there. Fantastic yeah.

R: Would you just tell me a bit about the circumstances around you receiving palliative care services?

P: Maybe I just got it because I was very badly treated in the hospital. Stuck in for seven months, and they were ignoring me. They thought it was in my head and I was in that much pain that I had to actually beg for them to send palliative care out. Cos I kept saying I was a patient of them.

R: Okay. And you were receiving treatment there. What type of condition do you have?

P: I have lung cancer.

R: So you came to then be receiving palliative care services. Kelly, Have you received any services from the hospice?

FCG: *Yeah, so I asked my mam, cos we were waiting a while. And because I just wanted to just kind of like, see, like, what it's like, you know, like, anything I can do to help my mam like, so I wanted to go in and just talk to somebody. So in the last two weeks, so two weeks ago I was speaking with Marie, one of the social workers there. I went into hospice and I found that really helpful. Yeah, so I have to see her in another two or three weeks time.*

R: So your experience you think has been broadly positive with palliative care?

FCG: *Yeah, I just kind of really wanted to see like, you know, like, how to like keep strong for my mam and like, what it's like for bereavement and all this kind of stuff. So she was very helpful and yes, I'm really, really happy I went in.*

R: Great. And how do you think that both of you are broadly kind of coping at the moment, independently and together?

P: Well at the moment now, I'm very, very, very ill, you know, so I'm kind of coming to the decision to come off chemo cos I'm on it since May and because I've been treated so bad, they just don't seem to give me 100% care in there. At the moment, I'm really

considering coming off chemo to have more quality of life. So that's a big that's a big decision now I'm kind of getting my head around the last few days. That's only because I'm so ill at the moment and I'm fed up being ill and I've lost so much weight I can't cope with the chemo anymore. I really want quality time with my family.

FCG: Yeah, like she's very independent. So like, like she's very strong and we're a really strong family and so like, she's always been so positive, but lately she does feel like just because she's been bed bound for a long time now that she feels like she should kind of like... not giving up but, she's just so sick of being feeling so sick. So like, it'd be good to get her back up to her normal self and have fun and to go out and enjoy things and do things together, like what we normally do.

R: Yeah, yeah. And how are you coping at the moment Kelly?

FCG: Yeah, I'm good. Yeah. Like at the start of the... like when you're waiting for results, it's very nerve wracking. And, like, there like, three or four months ago, she got the bad results, which they did in the [hospital name]. They kept saying it was just like it was just in her head, you're going through so much trauma, and like, all this kind of stuff. In the [hospital name], like when she was on big... the chemo, they said that they'll give her results in August. And then because she hadn't been eating since May, and going to the toilet and everything like that, she was just completely like, blocked, that when we got the results, then in like November that they actually apologized to my mam and said that they're sorry that the bowels are completely blocked now and the food hasn't been going to the bowels and that's why she's been so constipated. And that's her fairly untreated, for like, seven months, where... not all of them like this, I'm not saying they're all bad in there, but there was one of the doctors that she wasn't happy with that kept saying I have to wait for your results. I totally get that as well but...

P: They wouldn't listen to me, they kept saying it was in my head. And I definitely knew it in my heart, and one of the doctors said he was doing us a favour when I went in, so they all end up changing their tune then the next day, and everything I said, I was right. And that's what they say like, they took several months away from me. And they

wouldn't listen to me. It was absolutely a disgrace and I'm actually traumatized. I was meant to see a psychologist in there but because of the chemo was all over the place, because I'm quite ill, I can't an appointment with her at all. I actually feel every time I go in I'm nearly having panic attacks with anything to do with doctors because they kept fobbing me off. When I say I didn't ask them, I begged them, I begged them for help. But they think when you put on makeup and you look well, they think it's all in your head. That was my only outing I had to wear clothes I bought for the summer, and it was to go in and have chemo, that was my day out.

FCG: *She never she never really looks sick like you know, when you think of someone who has cancer, you think that they're going to be like, really ill looking. Now she has lost weight but she still looks amazing. She still gets up, does her hair, her makeup... no matter how sick she is. She does always look so well. So I think it's very hard if someone's looking at her looking so well, they're like, Oh, no it must be just in her head. Or you look so well, so how are you sick?*

P: That's not good enough.

FCG: *So I was very, like, angry and upset when I got the results. So that's why I went in to get counselling for a while because I was just I had to really accept that she was really sick when I found that she only had like a few months to live. I was so angry because for the last three years, I just kind of pushed it over my head until she was getting results and I never really kind of dealt with it like until only three months ago, when I had to make myself believe that it's not good for her like, you know?*

R: Yeah. Do you think that that experience has kind of impacted on the way that you are both coping at the moment? Like influenced it? Just do you think that that's the kind of distrust that you have... Is kind of influencing the information that you're getting at the moment and things like that?

FCG: *Yeah, yeah.*

R: Yeah, of course. And, getting up in the morning and putting your makeup on is important to you in terms of how well that... how well you feel? Appearing well, but not being treated as if you are ill as a result?

P: Yeah. When I actually how I think what they've done to me like, like, I almost died.

FCG: She got rushed into hospital and then they, like went to A&E and if it wasn't for the A&E crowd, like she wouldn't be here today. They were saying no you have to wait their results. And it was insane, the fact that they wouldn't listen, I was seven months. So you kind of do lose hope because you're kind of like, Oh God, what are they actually doing there? What are they saying, and you don't know whether to believe people or not now, you know?

R: Yeah, absolutely. And as for like your your life at home? Could you describe I suppose a bit about how you kind of rely on each other, like Louise, how you rely on Kelly, and then Kelly, how you rely on Louise as well.

P: Well what happened there about two weeks ago, was I had a terrible fall and I went down and my platelets went down really bad. I actually had a very, very bad fall. But I was dizzy all the time. And my other daughter, she was... she came in she started working from home. And Kelly working as a dental nurse, she'd come at lunchtime. But that was the first time I ever felt my independence was taken away from me. And I couldn't cope with it, I couldn't cope that they have to be there 24/7. Like I'd be afraid to go to the loo at nighttime and I ask now all the time. Now I found that's when I really want to go into the hospice, because I wouldn't like them to look after me like that way because I used to look after my own mother when she'd cancer and I wouldn't put them through it. That was extremely, extremely hard for me now. So lately, I'm just getting sicker and sicker. Now, I've had chemo last week, and I haven't bounced back. And I'm supposed to go again tomorrow and I'm so ill again. Like I just feel like the bloods are gone wrong, I'm just waiting to get dizzy again. I don't want to feel that way again. But that's like my kids like normally I just loved getting up and I just do my own thing and try to do as much as I can. But lately, I just find I've no energy. I'm

going downhill rapidly because I'm... I've lost so much weight. I've no... I can't even carry myself really. And I got makeup... that's even getting scarce now because I don't even want to get dressed anymore. That's how ill I feel all the time now I'm so sick, especially the last two weeks.

FCG: Yeah, like that's it like, it is kind of a bit hard like because like you know, when my sister's working from home and like, you know, like, if my mam does get chemo and stuff like that, like it is kind of hard like because you're kind of going to work and then Jasmine's working from home. My little brother works out of home and so do I, so you do worry, like, you know? And like, then like, my mam had to leave her job when she got sick. So like the financial like, isn't great. So it is quite... it is quite stressful when like you're trying to worry about financial bills and stuff like that, even though she's very sick.

R: Yeah, yeah. What did you work as Louise?

P: I used to be a carer.

R: Yeah, yeah. So you've experienced it kind of firsthand. Is that influencing your decision to go into the hospice, do you think?

P: Yeah, my mother had cancer so I used to look after her for a good few years, we thought she was dying for years. But like that I worked at a senior citizens home, so I would have been a real genuine carer. Like I've always loved to help everybody, and I'd give somebody help who needed it before I did, so I found that, really, kind of... before I got sick... why me cos I was always the one to help everybody else. So I just found like, when my mam died and I ended up working in a school, and I had a great relationship with everyone in school. And then I just kind of got cancer and my life just kind of came to... well I raised three children on my own, and I kind of felt I was coming to that age where I could actually make a life and I could actually leave the house and I could go and do something and then I was just hit by a rare cancer. Nobody knows that. But even now sometimes I'm angry. Because why me? I was always good to everybody else, you know, that kind of way?

R: Do you think as a result of that, maybe that you find it more... I hear you're saying there, you're kind of finding it difficult, the lack of independence. Does that make receiving support difficult?

P: Yeah.

R: Would it be more the physical support that you would find difficult to get rather than the emotional support?

P: Like that, normally, I'd always be the one to put up "Oh I'm fine!", I'd always put a front on even in front of the girls and my son, letting on to be fine. But then lately I don't... I can't do it anymore. Physically don't have the energy to hide it anymore. That kind of would really annoy me as well, because normally I'd be... I've fought this cancer for a few years. My motto was, like I had brain tumors, I had clots, I had... you name it. I've always bounced back and I just get on with things but once I had my independence, I didn't care. But I would always be jolly and get on with it. I'm just like, the way that I look at it, I never liked the sport groups, I never liked going to art, I never liked... The way I looked at it was, I have cancer, I'll be here when it happens and just get on with it and just live a normal life. And that's what got me through it. Instead I'd listen to somebody else's problems and I'd end up helping them and I'd be worrying about them. And I take that on, because that's who I am, I'd end up being going and helping them. Like when I see somebody with cancer, I'm like, Oh, my God, that poor girl and here I am, and I have it too! But I don't consider myself like that. I'd be the one to help them and I'd end up being top of their class as their support group, helping them out. So my motto was, just get on, just enjoy my family, and just get up and get on with it. And that's what kept me so strong.

FCG: *Yeah like we want to be able to bring my mam out, and like to like hotels because she can't fly anymore like. We had like a year like that she was... she was having like so much fun and like, like, we love to like bring her... like bring her out more places and stuff like that. And enjoy like... rather than her being staying in bed all the time like you know?*

R: Yeah, yeah, absolutely. What do you think is the best type of support that you think that you can give to your mom?

FCG: Like, time and love? Yeah, like that's, and just to like be there for her and help her and do as much as I can.

R: Yeah. So you think it's more the emotional side would be kind of more important than the physical side?

FCG: Yeah. Like, yeah, like, I don't know. Like, what physical... I don't know, like...

P: Physical! She can clean the house! [Laughs]

FCG: Yeah, like I am the cleaner in the house.

R: Yeah, yeah. What do you think, Louise? Do you think that's... Would you echo that? Or would you kind of have a different answer?

P: I try not to [seek emotional support]. Like I can see the hurt in her face and it's killing me. I could be like, you know... you can see when they're looking at you and you're trying to be like, oh, yeah, well, I am okay, but it is killing me to see them. And my son is a different case, he's kind of ignoring everything. But I worry for him because he's only 21. I find he wants to just... to just he doesn't want to know anything. He doesn't even want to account for it, and he's just like nearly ignoring me sometimes. You know, that kind of like? And he's so bad in the house, like he doesn't know how to do anything. I spoiled him as a child and a teenager, he won't learn even to cook. I tried the last two years but it's no, no, no. I worry about him a lot, because he wouldn't show the emotional side.

FCG: That's why I think the social work said to me that to... even if they're not, like just even just to say "Oh mam's like very well today" or, like, if we're all talking about my mam being sick or having a bad day, don't even include him in it but just let him... let him be in the room so he is listening to it. You know? It's really good support that I've... I've kind of learned from her.

R: Yeah. Yeah. And like, do you think that that actually is a support to your mam as well knowing that you're doing that kind of on her behalf?

FCG: Yeah, like that's what I should have had done yeah. Yeah, like I think like, it's good, because I want Jasmine and Cian, they're like my sister and my brother, like they don't want to go to counselling where I feel like, I really want to just, like, learn more about it, like, you know, like, like learn how to deal with the situation, and we do like suffer with anxiety anyway... my sister as well. So, we both suffered with anxiety before this happened. So like, you know, you do get good and bad days, and like you're trying to worry about your mam, and then you're trying to put your anxiety back as well. So, like, I wanted to go and get help, because I was very angry there like few months ago, because, like, I didn't know how to cope with the situation. So I want to help Jasmine and Cian as well. When... if anything did happen or if it's just to learn more about, like help with situations like that, because we've never had to deal with this before.

R: Yeah, so you're basically empowering yourself to be able to cope better by accessing the services? Yeah. And that you're helping the others as well? Do you think that helps you and your mam?

FCG: Yeah, yeah. Like I'd like them to because like, like, I just want to like, I want to like learn it see if I'm missing anything or like sometimes you're just kind of in like flight mode that you're you don't really sometimes you don't really see what's actually going on around you because you're kind of your head's all over the place. You know, I want to be able to sit back and somebody to make me realize you know, to see it like.

R: I know you're saying there Louise that you're trying to make the decision at the moment whether to stop chemo... Could you talk me through the process of that of making that decision with your family? Or how just how you would go through that decision making process what does that look like?

P: I only kind of made the decision yesterday, so it's kind of up in the air. Now I'm supposed to have chemo tomorrow, but I feel like I'm very weak for it. But like I was so sick this week like, I was like awake like about three nights in a row now, and three

o'clock in the morning I was taking panic attacks I was so ill. And I was just lying there and you know the way you feel just like your whole body... because I'm on the chemo, I feel like it's just damaged every single cell in my body. And I was just lying there like and for the first time... for the first time I felt depressed and fed up. When I just... the other night I was so sick, I just wanted to die and I never felt that way before. I just go on and on and on and I don't seem to be getting any breaks lately... literally one thing after another, where before I used to have like two weeks off and I'd kind of bounce back. But now I'm not getting any breaks whatsoever and then I just feel like... last night and the night before, sure what life is this? This is no life, to be sitting here feeling so miserable. Like if I came off chemo for like a while, like I don't know how long the cancer... because cancer has gone to my liver now which is bad. So I'm in big trouble. Big big trouble. So at the end of the day, I've a scan now at the end of the month and... that'll tell everything now as well. See if it's gone somewhere else and if that happens, well then I know that the chemo's not working and the cancer is spreading rapidly, so my decision would be if I didn't have chemo and now hopefully... I'm hoping I bounce back, because I didn't have it at Christmas and I was able to enjoy the family and do things. I was able to get up and get dressed and have a shower without any problem. So I want to be able to do that and then to be able to go out and have dinner, well I can't eat but to be able to even go out, pretend I'm going for a meal. But just to be able to go out and even walk on the beach, to be able to do things like that. To be able to do and feel good for a while. But that's my decision because like there's no life just the way I'm living at moment and miserable like. Some days I bounce back but like it just seems that I'm only getting a week off that misery again and it's getting worse every time now because... we because my bloods are all failing as well now... is it the platelets I think they call it? They're all low now at the moment, and that's causing me to be dizzy. So, it's only getting worse now, my body is reacting to the...

FCG: Her body is so weak from the chemo like, but I think she should go in and say it to them tomorrow and see and then even get chemo tomorrow and then the following

week and then just to see before she makes that decision, to see her scan before she makes that decision, but that's entirely up to my mam.

P: It's early days now as I say I only made the decision last night.

R: Yeah. Unknowing, would you take say, like, like Kelly's advice there, would you really take that into account? Or would you kind of end up going with what you thought in the first place?

P: Well I know like they don't want me to die and I know like when I come off chemo that's what they're thinking, I'll die quicker.

FCG: No, no. Like, I... I'd like to... like for you to make your like... I want her to make her decision just to see... Like, I'd rather have... I wouldn't like to see her in pain.

P: I know that but I think everything is going to determine on this scan now, really we have to wait for this scan really. Like even if this gave me a month off just to give my body a chance to recover. Cos I may not have a month you know that kind of way? Like, I can feel myself going down rapidly like myself, you know?

R: So rather than a group decision, it's kind of Louise, it's your decision that is supported by your family or...?

P: Yeah. That we talked about yesterday. And I talked to my other daughter as well, and even my other daughter said, like, you're miserable. I'm just so depressed now at the moment, which I never felt before. And just kind of because I think because I've been so sick like I'm just fed up now at this stage, like you can only take so much like. I feel like I've taken all I can take at this moment.

R: Do you do you find yourself still being a support to Kelly as well as being supported by them through this process?

P: I'm like the counsellor in the house!

FCG: Yeah.

R: What is that kind of...? Do you think your role has changed at all as? Or do you think it has stayed the same?

P: I think it's the exact same when it comes to advice, I'm always very good at giving advice I can tell you that, and I always like to see them take it, you know with relationships and all different things. And they've always said it, like I've always given the best advice and I love doing that, because I want my kids to be... they're brilliant kids inside and out. I'm so proud of them. I love to be able to help them when things happen, but they would come to me still if there's a problem about anything and I want to look out for them but just because I'm so independent and so strong, I want to keep that role, still to the end. I don't tell them my problems, but now I am because I'm just being sick... I think this is the first time I've told them how I'm feeling which is very important I suppose you know that kind of way? Because it's like knowing your body is breaking down, that means I just keep telling them I want to tell them I love them all the time like.

R: Do you think you're benefiting from the that emotional support that you haven't really had into before?

P: Oh yeah, you know what, we're like friends as well like. We tell each other everything like there's nothing we don't tell each other, like everything, even my son when he has a fight with the girlfriend that's the only time he ever opens up but other than that he'd tell you nothing. But he'd still come to me for advice about different things, like work or different things like. I help him that way. It's hard for him though, sometimes he just wants to go up and play Playstation and I think that's his way of coping but as well. I do feel sorry for him because like he's very stubborn and I want to say just say "Come on we sit down and talk" but he won't. He'd be a worry because he's so young, like even though he's so tall and he looks so much older but he's very immature really so I worry about him like a lot.

R: And Kelly what do you think is the best support you give to your mam, and the best support you get from your mam?

FCG: *Em, yeah like the same I just think the best support from my mam is like she's always leading me on the right track, she'll see things that I don't see and she's always there when I need her like, always motivating me and making me strong even though like, sometimes I can't be strong. She'll always snap me out of it, she's always there supporting me and helping me. And then for my mam, I just..., forget the question you asked sorry!*

R: The other question was just what do you think is the best support you give to your mam?

FCG: *That I give to my mam... it's real cheesy like! I don't really know. Just the same as what my mam said like em...*

P: Because of how it feels to be us, we've kept it so normal kind of house. But she'll come in and ask me how I am and of course, there's anything I ever want from them if I need stuff doing, and like that too like I am asking for a little bit more help this week because I can barely get down the stairs or up the stairs, and but she's very good in supporting me that way, and as I said, before we didn't talk much about cancer. As I said to you, we just deal with it when it happens, that's the way I do things. But if this was a decision that was completely new, my decision last night with the chemo. It's new to us at the moment so I know now Kelly will talk more about that to me because there's something new on the horizon, I'm actually making a decision about something like, I'm actually bringing them into the equation or I wouldn't have brought them in with something like this. So they're very supportive I know the two of them... even from yesterday are completely supportive about this which I really appreciate. And I know it's killing them thinking "Oh god what if it goes quicker" but as I said we have to wait and see as I said the scan. But the support will be there because I'm opening up a bit more because I'm so ill.

FCG: *Yeah like, it is really... I actually feel sick thinking about it cos sometimes you just forget about it and sometimes it hits home then. And it's really upsetting when you hear it because sometimes you don't believe in it just like, that it's true, it's just like a*

dream. Because we are so close we're always there for each other, we're always good friends, like you know we always have a laugh together, we're like the same people like. Aren't we?

P: Very much so yeah.

FCG: *Yeah so it is very hard like you know?*

R: Yes, I can hear that you get along! When it comes to obviously making that adjustment really quickly, like you say you have only been getting proper information in the last little while, but say when it... Louise you were saying you might want to become an inpatient in the hospice, would that be a group decision as well or is that something you've decided in your own head?

P: That would be my decision because there's no way that I thought I became like incontinent... no. Because it's lung cancer, it goes to the brain and I've already had two brain tumors now. If that goes to the brain I could be paralyzed, and the last time I lost my speech for a while, and then I had radiation, but like if that happened and say if I was paralyzed or I couldn't speak or I couldn't really look after myself again... If that was taken away from me, that decision will be just mine completely. They're not going to look after me, no way, and that would be final. I told that to the nurse that there's no way they would be changing me. They wouldn't be doing something like that. I wouldn't be able to cope with it. Near the end I'd just prefer them to come in and visit me, if there's things to be done... but that would be my decision now. Big time. They're not looking after me if I became incontinent or paralyzed or you know.... like you don't know where it'll hit the brain either you know? The way some people get angry. But no, I wouldn't like them to see me like that or look after me like that. That's my independence again, I wouldn't be able to cope even thinking about it. I'm nearly breaking out in a sweat like thinking about it. So no there's not a chance I'd let them look after me like that.

R: So you think it's more out of responsibility to your kids rather than say your preference?

P: Yeah oh God yeah

FCG: *Like I would love to be here for my mam you know obviously like it's her choice. I wouldn't be happy with her going to the hospice but it's her choice like... so me and my sister would have to chat about it.*

P: Well they say that now until they're looking after me 24/7, because I know myself my mother had cancer and it was very very hard work and I was very well able for it when it was my generation. I said I would never put him through that. It was very difficult and I loved my mother and I didn't mind, but I'm a different generation to that generation. They have to get on with work and things like that. Of course they'd come into the hospice and things like that. I would [go into hospice] because I'm so independent that would kill me now.

R: And Kelly would you try and influence... not influence but would you want to sit down and talk about it further rather than just accept what's the current situation?

FCG: *Yeah, yeah. I would love to help my mam like you know because she's done so much for us as a single parent like she was always there like, so I think that would be nice to return the favor like if it ever got that bad. Obviously it's her decision but me and my sister would love to help out and obviously would have to leave our job and be a carer but that wouldn't be an issue really like. The only thing is... and it's so annoying, but you have to worry about the finance of the house and stuff like that... that's the only thing that's really annoying. When someone has cancer there should be help out there like... because obviously my mam's not working and we have a mortgage and she's a single parent, she always was since I've been like 10.*

P: Isn't that awful?

R: Absolutely. Well, that's actually the end of my questions, but I'm just wondering if there's anything else about your experience that you would like to discuss, that the questions haven't really addressed? Is there anything else that you want to be heard?

P: The doctors need to listen to patients' cause at the end of the day it's my own body and I wouldn't like this to happen to anyone else and I mean like... even in the beginning, when I got cancer, I was very ill, very up and down as well, and I remember asking questions and I want to know exactly how it is. I don't want any sugar coating on it, I wanted exactly as it is. So I find if the patient asks that, she should be entitled to get the full truth and nothing but the truth. When I got cancer you know... the way you always see all this... the hospice is different, I've heard it's fantastic but it's nothing like that... when you go into a cancer ward, you're just a number. I think it should be a lot better and I hate when I see young people on their last... God love them. See again, there's me worrying about them! Seeing like a young girl probably like yourself going in, and I might see her then for three or four weeks and she's no hair. My heart breaks for her. They shouldn't just come along and give chemo. There should be a bit more support if there [hospital], because you see it all in this movies and you think "Oh God I'm going to be treated like really really good as a cancer patient", and you're actually just a number. Just like you're a conveyor belt. Going in and out. Now don't get me wrong, the nurses are so busy and they have to do their job, but there could be other people around that would talk to the patients... especially a young girl or a young boy going through something like that like. It's horrific like. I'm nearly 58 and I'm saying "Well at least like I've had a life" like. When you look at people... like imagine the trauma that would happen if you discovered it. There's no support like I don't think there's anything... I think the way you see in the movies it should be like that with support. If you're feeling down all they come along and say is "Go over to [counselling service] across the road" and that's all you're told in terms of support. I remember going to [counselling service] once but it wasn't for me. I felt really out of place from day one, but like I think there definitely should be more support for young people you know when they're all diagnosed first. I think you're just a number when you go in there, because I've had a lot of dealings with them [hospital] over the last three years so I didn't... I remember being very angry in the beginning because I had been told different things, but like that's what I would definitely say... they could do something to help.

FCG: *Yeah and I think like the car parking... I feel like you should get like a free pass because obviously like you're dropping your mam in, and when I'm dropping around for chemo you've to go and pay or park and get her to wait there. Like the last time she was feeling faint like you're afraid she's gonna faint and you can't park outside the hospital. Or like you're trying to go up and then you're worried about if she's going to pass out or if she can't walk that far from the car park... I think you should be able to park wherever if you're dropping somebody in for to get chemo. I think it should be less stress if your family member has gone through that like... There's no real financial help at all. The last thing you want to do is be worried about that when someone is actually dying or is really really sick. I think there should be a lot more support for that kind of situation.*

R: And Kelly you're obviously a young person to be going through this experience... is there anything that you would say about your experience as a young family caregiver?

FCG: *Yeah, I think just kind of to push on and to be like positive. Try not to talk about cancer as much and just to live a normal life... and enjoy the moment and live a normal life even though sometimes it's hard. Yeah... just sometimes not to be depressed 'cause obviously if I was depressed, my mam would be sad, and she's worried about me then... where she should be [worried about herself]... it should be all about herself and that's it. You just kind of have to be all about them. I know it's hard sometimes when you're going through your own boyfriend troubles or like your troubles yourself...*

P: Yeah just live in the moment, that's what got me this far, I swear to God.

R: Day by day kind of thinking?

P: It's like that too... if you're gonna sit there and dwell on it, you're going to be down. What is that going to do for you? Because at the end of the day you have to get up and say "Well today is another day in my life. The sun is shining and something is happening. I'm going to have a great day." Can you say that to yourself? But what if you got up and you said "Oh God I have cancer. I'm going to die, blah blah blah." You're

going to feel miserable, so I think you should wake up and show that. We have a great laugh here and we're always joking and messing, you know, things like that. Before, I used to have a glass of wine... I haven't drank in seven months and I missed that. Well, we sing together and have a laugh and play cards and things like that, where we never talk about cancer.

R: So you think it's important to compartmentalize that?

P: Yeah, yeah, because at the end of the day, my thing was "I have cancer and nothing's gonna stop it, no, there's nothing anyone can do". Cancer is just terrible, but there's nothing you can do about it. Once the cancer takes you, it takes you, and at the end of the day nobody can help you, so what's the point in thinking about it or Googling it or all this sort of stuff? Get your treatment. But at the end of the day, cancer will get you in the end like, so you're better off dealing with it when it actually happens. The way I'm dealing with it... it's hard now, don't get me wrong, but making decisions like this and then thinking you're going to die... I don't know how I'm going to feel in another two weeks' time... I can't stop thinking about when I get chemo. I don't know what it's going to be like' cause I've never experienced it, so I keep just saying to God "Please God just make it fast and don't let me suffer anymore". So I hope I go quick like if it happens. That's all. I'm kind of hoping for not lying in the hospice for months and being in pain and not being able to walk or do something like that, you know that kind of way? So that's another chapter I have to face as well, like down the road. You wouldn't know how quick it's going to go, but I get up every morning. That's what I want to do, I want to get up now and get dressed, have a decent shower and just get out and go for a walk on the beach. That's all I want now at the moment.

R: Yes, it's really interesting what you were saying there about having a laugh and sharing sense of humor as well, it seems to be really important to you?

P: Yeah, we always have a great laugh. We've always done it like, so like I'm an awful messer like. I get on great with their partners and we all love each other. We just get on so well with each other. It's amazing. I'm really hoping I'd say anything to them, you

know that kind of way? I want them to feel “God I can talk to her, I could say anything to her” so that's great. I've always been like that, I'm so straight but like it works! And I do be talking about sex in front of them and everything! And they're saying “Oh my God, I can't believe she said that”, but it actually makes it more comfortable if you get me, because they don't have to be like “Oh that's the mother, I can't say anything now”... but that's my motto anyway keep everything happy anyway.

R: That's brilliant Louise, I'm going to stop the recording now if you're happy with that?

P: Yes, thank you.