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Experiences of family carers of people with cancer receiving home-based end-of-life care services

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ABSTRACT

Aim: To explore family carers experiences and perceptions about formal support services received while caring for people with cancer at home during the last year of life.

Background: Cancer is a major leading cause of death globally. Family carers of people with cancer experience significant challenges during their caregiving journey that are intensified towards the end of life. Supporting family carers of people with cancer is required for promoting their well-being and enhancing their caregiving coping, which implicitly influences the quality of caregiving provided at home for people with cancer. Although several studies have explored caregiving phenomena, many of them approached formal support in a descriptive way. However, an interpretive experience of formal support seemed to be limited, especially for the end-of-life period. Different support services are offered to facilitate family carers' coping such as practical support, respite care, and emotional support; however, family carers reported varying experiences and satisfaction. Further research is needed to explore the contextual and experiential variations for either satisfaction or dissatisfaction with formal support and their role in empowering family carers while considering the impacts of the end-of-life trajectory on caregiving dynamics and experiences.

Study Context: This study was undertaken in the UK community healthcare setting.

Methodology: Constructivist grounded theory approach was used. In-depth, semi-structured interviews were conducted with 26 family carers

of people with cancer. Constructivist grounded theory traditions guided data collection and analysis.

Findings: Three major categories were identified: living in the chaos of caregiving; interacting with formal support; feeling rewarded versus guilt and regret. These theoretical categories contributed to the development of a substantive theory of facing the caregiving chaos in the light of formal support, which described the essence of family carers' experiences.

Conclusion: Family carers experienced different sources of chaos while caring for people with cancer at the end of life. However, their ways of coping and formal support interactions interplayed in this context, which yielded a collective experience of reward or guilt and regret. These findings provided new insight regarding the role of formal support in the facilitation of long-lasting, rewarding experiences. The present study provides several implications to enhance family carers' support, such as enhancing work support policies and providing family-centred care. Future research is needed to explore the relevance of the proposed theory for family carers in other patient populations and in other caregiving contexts.

RESEARCH DISSEMINATION AND GRANTS

Abstract:

- Sharaf A, Whittingham K, Diver C, Clissett P. Opportunities and Challenges to Family carers End of Life Care Research in the COVID Pandemic: A Researcher's Reflections. In 7th Public Health Palliative Care International Conference. Palliat Care Soc Pract. 2022 Aug 13; 16:26323524221119941.

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LIST OF ABBREVIATIONS

FC/s	Family Carer/s
PwC	Person/People with Cancer
EoL	End of Life
EoLC	End of Life Care
CGT	Constructivist Grounded Theory
COVID	Coronavirus disease
NHS	National Health System
WHO	World Health Organization
NICE	National Institute for Health and Clinical Excellence.
GMC	General Medical Council
CASP	Critical Appraisal Skills Programme
PROSPERO	International Prospective Register of Systematic Reviews
HRA	Health Research Authority
R&D	Research and Development
PPI	Public Patient Involvement
PPE	Personal Protective Equipment
CCGs	Clinical Commissioning Groups
RCTs	Randomised Controlled Trials
ADLs	Activities of Daily Livings

CHAPTER ONE: THESIS INTRODUCTION

1.1. Study relevance

Family carers (FCs) play a vital role in the provision of care at home for People with Cancer (PwC) at the End of Life (EoL) (Funk et al., 2010, del Rio Lozano et al., 2017). However, their quality of life and wellbeing are greatly affected by the caregiving process (Jadalla et al., 2020). Although FC's support got more attention in recent decade, a call for evidence survey released by the Department of Health and Social Care (2018) about how carers could be supported highlighted that FCs responses about the state of support tended to be brief and that FCs were inclined to focus on negative situations. Similarly, the narrative review results produced for this thesis Section 3.4. noted that most research investigating FCs' experiences of support was descriptive in nature, and the notion of support was only a complementary part of caregiving studies (BrobÄCk and BerterÖ, 2003, Brazil et al., 2010, Johnston et al., 2012, Seal et al., 2015). Meanwhile, the notion of FC's support during EoL trajectory requires further exploration (Penrod et al., 2012). Thereby, the purpose of this PhD study was to achieve a better understanding of the FCs of PwC formal support experiences at home in EoL and provide valuable recommendations for enhancing the FC's support.

1.2. Researcher's position

Having a nursing background and previous working as a critical care nurse in acute setting gave me the opportunity to care for several cancer patients and their families and attend to their suffering and

provide them with support. Similarly, during my academic clinical work as a teaching assistant in community health nursing, I engaged with people who had chronic conditions and perceived that most of them preferred to be cared for at home. However, this depended on the readiness and abilities of FCs as well as the support they received to deliver optimum care at home. Moreover, my personal experience of witnessing the family caregiving of an elderly relative until EoL sensitised my thoughts about caring responsibilities and their impact on FCs. All these insights and experiences shaped my expertise and interest in exploring the support experiences of FCs of PwC at EoL at home in my PhD thesis.

1.3. Thesis structure

This thesis is presented in six chapters that follows this introductory chapter. Chapter two includes a background context of cancer, caregiving, EoL and FC's support; Chapter three involves a narrative review about the experiences of FCs of PwC regarding formal support at home at EoL and concludes with study aim and objectives; in Chapter four, methodological approaches such as the research paradigm, study design, recruitment, sampling, data collection and analysis process and researcher reflexivity are described; Chapter five reports the study findings; Chapter six included a discussion of the findings and the developed theory in the light of other studies and theoretical models; lastly, Chapter seven highlights the contribution of this study to knowledge, possible implications, critical appraisal of the study and conclusion.

1.4. Key stakeholders in the study

Three categories of individuals were the key stakeholders in the caregiving and support interactions in this study. Firstly, the person who provided family caregiving was identified as a family carer (FC); this applied to relatives or friends who provided care for the PwC. Secondly, the person or people cared for were identified as Person or People with Cancer (PwC). I found that this term was suitable to describe the disease context in which caregiving took place. However, when FCs and PwC needed to be mentioned together, the term caring dyad or dyads was used to illustrate the caring relationship. Formal support was provided by many individuals who were related to the healthcare field, such as physicians, nurses, and paid carers, so that they were identified as Health Care Professionals (HCPs) in this thesis.

1.5. Study context

In this study, the experiences of FCs of PwC in the community setting were explored. Participants were living in two English regions; East Midland and Southeast of England. Various support services were experienced such as HCP's visits, out-of-hours support, night sitting and social care support. The research process (e.g., participants' recruitment, and interviewing) and the most of reported experiences of FCs occurred during the global Coronavirus Disease*** (COVID-19) pandemic (2020-2021). In response to the pandemic, social distancing and national lockdown were enforced in March 2020. Then, non-essential healthcare research activities were paused and in-person research activities (e.g., interview) were transformed into remote form (i.e., online) whenever

possible. This resulted in experiencing significant challenges in study set up and participants recruitment which will be explored in Section 4.5.2, 4.5.4. The pandemic context also affected the provision of formal support services to PwC and FCs; HCP's consultations and visits were mostly conducted remotely and delays in support access were experienced by FCs in this study due to pressures on healthcare services and staff sickness during this time.

*** A highly infectious respiratory disease that is transmitted by close contact, respiratory droplets and getting in direct /indirect contact with mucus membranes in mouth, nose, or eye; severe COVID infection can cause respiratory failure and potential death (Carter, 2022)

CHAPTER TWO: END OF LIFE CANCER CAREGIVING

2.1. Chapter introduction

This chapter discusses an overview of cancer and the background of the family caregiving phenomenon. The prominent theoretical models used to explore family caregiving will also be considered. Then, the chapter elaborates on notions of the End-of-Life Care (EoLC) and FC's support and the related major initiatives.

2.2. Overview of cancer

Cancer is considered a leading cause of death globally (World Health Organization, 2022). In the UK, according to Macmillan Cancer Support (2022), cancer incidence has increased by 39% since 2002. For instance, the number of people diagnosed with cancer in England has increased from 284,780 PwC in 2002 to 392,466 PwC in 2020 (NHS, 2022). Cancer is described as a condition that involves irrational and non-controllable cells multiplication that negatively impacts the functions of the body's organs (Miller, 2018). In some instances, these cancerous cells transfer through the body and grow in other locations; in this case, it is described as **"Metastasis"** and is usually associated with a poor prognosis (Miller, 2018). The spread and size of cancer lesions are usually described by a numerical system that involves four stages (Cancer Research UK, 2020):

- Stage I: describes a local and small-contained cancer.

- Stage II: describes larger cancer lesions that have spread or have started to spread to very close lymph nodes.
- Stage III: describes larger lesions that started to spread to nearby tissues and lymph nodes.
- Stage IV: describes cancer spreading to other body organs, which is defined as metastasis or secondary cancers.

Cancer incidence and mortality escalate rapidly with the increase in ageing and population growth in general (Bray et al., 2018). Several risk factors are associated with cancer incidence, such as tobacco and alcohol intake; unhealthy eating and physical inactivity; and exposure to pollution and infections (Lortet-Tieulent et al., 2020, World Health Organization, 2022). Globally, the most common types of cancer in 2020 are breast, lung, colorectal, prostate, skin, and stomach cancer with a high mortality incidence of lung, colorectal, liver, stomach, and breast cancer (World Health Organization, 2022).

Wilkinson and Lynn (2005) argued that the cancer experience is characterised by suffering and an increased level of dependency. PwC experience a variety of health complaints due to the impact of disease and treatment adverse effects (Stark et al., 2012). Pain was identified as the most common cancer physical complaint that led to emergency department visits (Batalini et al., 2017, Son and Chung, 2022). However, other symptoms may include fatigue, gastro-intestinal complaints (Son and Chung, 2022), and psychological problems such as depression

(Tsaras et al., 2018). Meanwhile, cancer symptoms and complaints tend to exacerbate toward EoL and possibly involve deteriorated levels of consciousness and agitation (Hauser and Kramer, 2004, Seow et al., 2011).

The trajectory of chronic diseases is considered a unique characteristic of each disease that enables us to track illness changes and deteriorations and plan for the patient and family support (Wilkinson and Lynn, 2005, Reed and Corner, 2015). Corbin (1998) described illness trajectory as a concept involving the disease course as well as the behaviours to manage the course of illness, which ultimately influences FCs' experiences when they support a person with chronic illness; each trajectory will determine the nature of support needs (Lunney et al., 2002). In their review, Wilkinson and Lynn (2005) reported three different terminal illnesses trajectories (Figure1.1-3). The illustrated figures portray the course of different illnesses and their EoL characteristics. For instance, although cancer has a long period of stability and determined terminal stage, it is characterised by a swift decline (Figure1.1.). In organ failure trajectory (e.g., heart failure) (Figure1.2.), the decline occurs over a long time which is intermittent by periods of stability; however, it is associated with a sudden death. In other disease trajectory (e.g., dementia) (Figure1.3.), the deterioration occurs steadily over a long period of time before death.

Terminal illness trajectory (Cancer)

Prolonged period of stability with rapid decline and a defined terminal stage.

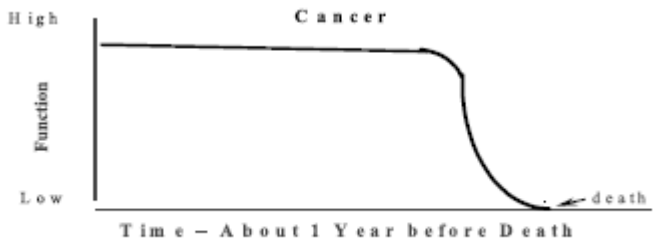


Figure 1.1

Organ system failure trajectory

Long period of declining with intermittent instances of deterioration and stability and a sudden death.

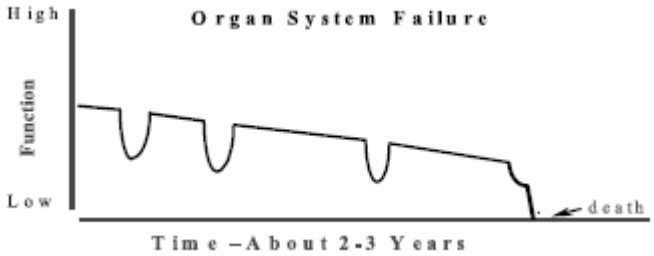


Figure 1.2

Dementia/frailty trajectory

A steady decline over long period of time prior to dying.

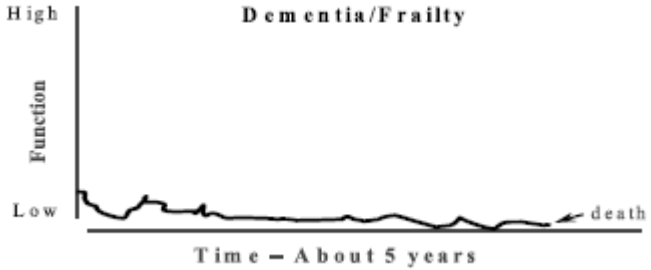


Figure 1.3

Figure 1.1-1.3. Terminal illness trajectories adopted from (Wilkinson and Lynn, 2005)

These differences in illnesses trajectories results in differing patients and FCs support needs. For instance, PwC usually suffer functional decline and symptom worsening towards EoL, while they might be quite independent to perform the usual activities of daily living in the last few months of their lives in some instances (McCarthy et al., 2000, Ellershaw and Ward, 2003). In their study, Teno et al. (2001) quantitatively examined the functional decline in different diseases including cancer. They found that PwC experienced sharp deteriorations in the last five months of their life compared to other diseases such as, heart failure and stroke who had more gradual decline. This suggests that cancer caring dyads would have increased support needs towards EoL that should be timely arranged to facilitate dignified death.

Cancer survivorship has improved by about 10% in the UK as a result of early detection and management (Reblin et al., 2016, Department of Health and Social Care, 2023). However, non-curative cancer is considered a challenge for PwC and their FCs; the challenges are attributed to increased symptomatic burden and unmet palliative and EoLC needs (Maher et al., 2015, Haun et al., 2017). A systematic review exploring the unmet needs of partners and caregivers of adults diagnosed with cancer revealed greater unmet needs for palliative FCs than others who cared for cancer survivors (Lambert et al., 2012). Unmet needs include comprehensive cancer care, e.g., care coordination and continuity; emotional support; dealing with disease impact on FC's life such as work and lifestyle; relationship's support with PwC and other family members; informational support; and spirituality (Lambert et al.,

2012). This suggests the importance of exploring the perceptions of cancer FCs regarding formal support that would address these unmet needs.

2.3. Family caregiving in cancer

Demands for family caregiving are projected to increase with the movement towards reducing hospital stays and the transfer of care into the community (Collins and Swartz, 2011). Pickard (2015) projected that a family caregiving gap would emerge from 2017 onward, with about 160.000 shortages of FCs by 2032. It is estimated that 20% of adults are currently classified as FCs in the UK (Carers Week, 2022) and about 60% of FCs are women and most FCs' age fall between (45-65) years; more than half of the adult FCs are working while caring (Foley N et al., 2022).

Family caregiving in general contributes to economic advantages and cost savings in healthcare provision and expenditures (Hauser and Kramer, 2004, Duggleby et al., 2017). In financial terms, according to the Houses of Parliament (2018), family caregiving was estimated at a value of £57 billion to more than £100 billion every year; the cost of family caregiving was found to outweigh the value of paid care provided by the governmental sector in 2015/16 (Houses of Parliament, 2018).

Defining family caregiving has been a matter of debate regarding the appropriate conceptualization of this term. For instance, caring could be conceptualised as pertaining to the innate trait of supportive individuals who care about others, which is considered the essence of

human nature (Griffin, 1983). Other authors such as Dunlop (1986) and Cooley (1915) argued that caring is a sort of relationship that is built upon a sense of duty and concern for the person being cared for, which is found naturally in social and family relationships (Pearlin et al., 1990). This contends that caring incorporates two aspects that involve instrumental tasks of support and attending to the social and emotional needs of person cared for (Qureshi and Walker, 1986). However, to illustrate a more clear conceptualization of caring and caregiving, Pearlin et al. (1990) alluded that caring and caregiving are different terms; caring represents the emotional part of the provision of care where FCs feel committed to others' wellbeing, while caregiving describes the practical tasks component of care provision. By analysing these different connotations related to caring and caregiving, it can be argued that they could be used interchangeably; however, family caregiving would be more suitable and comprehensive to describe the actions of giving care that contribute to practical tasks support and not only implies emotional aspects. Although **"Family caregiving"** is a suitable term to describe the process of care in the context of caring for terminal illness in this study, the person who provides the care will be described as **"Family carer"** rather than **"Family caregiver"**, since this term is more contextual and usable in the UK (Levine, 2016).

Family carers are described in various ways, which is linked to the different approaches to the caregiving process highlighted earlier. Some authors such as Harding (2013) described them regarding their practical duty of care. Harding (2013) identified FCs in terms of their role as

unpaid, informal supporters who provide one or more physical, social, practical, and emotional tasks for the patient. The author used the term **"Caregiver"** to include other people who would contribute to the care, such as friends (Harding, 2013). This description is inclusive and differentiates between FCs and HCPs through the **"Unpaid"** notion. However, using the term **"Informal"** would imply that FCs do not need skills training, recognition, or support since it impedes the standard personal tasks, e.g., personal care, that are feasible for anyone to do (Stall et al., 2019).

Okamoto and Harasawa (2009) added a specified duration of caregiving in their description, in which FCs are family members who provide a minimum of one hour of daily care for at least 3 months for the person cared for. This is a restrictive description that does not consider the impact of caring for a person with rapidly declining prognosis that would last less than three months (American Psychological Association, 2020). Other FCs' descriptions extended the scope of FCs' relationships where they are not restricted by blood or marriage relationships (i.e. family members), but they extend to include other people who have a close social bond, such as neighbours or friends (National Institute for Clinical Excellence(NICE), 2004, Xie et al., 2016). Some authors, such as Wahid et al. (2018), identified the essence of lacking the caregiving experience and training while engaging in the caregiving process that differentiates between HCPs as carers and FCs and illustrates their need for support; however, this approach would ignore FCs who have previous

experience of caregiving through their work as HCPs or caregiving for another person, as evident in some cases of this thesis.

Family carer's residence arrangements are another aspect that was highlighted in some FC's descriptions where they are identified as persons who may or may not live in the same household with the person cared for, which extended the scope of FC's definition (Hauser and Kramer, 2004). Considering these conceptual variations of FCs; it could be argued that these different descriptions would complement each other and provide a comprehensive approach to FCs' defining characteristics. For the purpose of this study, an open description of FCs was perceived as necessary to maximise recruitment and explore different aspects of the caregiving context; thus, FCs are operationalized as persons who provide the care to PwC that may involve, but is not limited to, physical, emotional, and social care. They would be members of the family, friends, or neighbours who might or might not live with PwC in the same household.

Family carers engage in multiple tasks to care for PwC at home (Girgis and Lambert, 2009). Meanwhile, to best address FC's roles, it is worth noting Bowers (1987) typology of family care. In her grounded theory study of intergenerational caregiving, she identified five categories of caregiving tasks that FCs do, and some of them were considered even before the person they care for needed support. The author argued that **"Anticipatory care"** starts prior to actual caregiving and represents the proposed plan of action if care needs would exist. Another form of care that existed prior to actual practical hands-on caregiving tasks taking

place is "**Preventive care"** which involves remote monitoring and checking of the person cared for to make sure that their health is under control. Then the type of care advances to "**Supervisory care"** that involves actions, e.g., checking out persons cared for and arranging services for them; however, with increased engagement of FCs with practical tasks, e.g., help with moving and personal care, **"Instrumental care"** starts. "**Protective care"** is the last type of family care that involves efforts to hide the diagnosis, the impact of illness and associated support needs and dependency from the person cared for to protect their emotional wellbeing and self-image. This category of family care is criticised as providing limited benefit for some persons cared for, e.g. PwC, since it would be necessary to disclose the diagnosis and its impact to them to plan their future actions (Nolan et al., 1995). However, Bowers (1988), then used the term **"Preservative care",** which would be more appropriate to deal with the limitations of the progressive illness and develop a new way of life (Nolan et al., 1995)**.** This type of family care involves efforts to keep the person cared for living as normal as possible, maintain their dignity and self-esteem, and limit the incidence of emotional breakdown due to a feeling of personal insufficiency (Bowers, 1988, Nolan et al., 1995). Nolan et al. (1995) extended Bowers (1987) family care model, where he argued that anticipatory care would be practised throughout the progressive disease trajectory and change in nature. This would be applicable in the case of PwC, where their care needs would change and require a different level of FC's support.

Furthermore, Nolan et al. (1995) acknowledged that preservative care is more linked to the previous state of abilities of the person cared for; however, he argued that is not enough since there is a need for the restructure of the new roles and perceptions of abilities to develop a new normal, which is described as **"Reconstructive care"**. Nolan et al. (1995) also identified another new category of family care **"Reciprocal care"** that involves the perception of the giving back behaviours exhibited by the person cared for in response to the FC's efforts, e.g., verbal gratitude and acknowledgement. This suggests the possible sense of achievement and reward that could be experienced through this type of care. This implies that family caregiving can be a bi-directional process where the person cared for, and the FCs can both find benefit and gain. Although these models of family care are useful in exploring the FC's roles, they were developed in the dementia field and parental caregiving (Nolan et al., 1995). However, they provided a foundational direction for FC's support, which will be discussed later in Section 2.5.

In the context of cancer caregiving, several FC's roles exist that involve complex, and multifaceted tasks. Cancer FC's roles can be classified into two broad categories; direct care, which pertains to tasks that are carried out with the PwC, e.g., personal care, symptom monitoring and management, medication administration, and emotional support; and indirect patient care tasks, which involve dealing with activities on the PwC's behalf, e.g., coordination of healthcare services, medical transportation, and dealing with finances (Given et al., 2001, Kim and Baek, 2022). However, these tasks and associated burden become

more intensive and complex with the deterioration of PwC, symptom exacerbation, and increased dependency levels as they approach EoL (Given et al., 2001, Wilkinson and Lynn, 2005).

This suggests that FCs are expected to master complex duties and responsibilities that need training and support from HCPs (Girgis and Lambert, 2009). However, the current evidence indicated that cancer FCs have a range of unmet needs. For instance, in an Italian cross-sectional survey of 87 cancer FCs, many FCs indicated unmet needs regarding interaction with HCPs (Zavagli et al., 2019). FCs in this study reported that HCPs showed little concern for their emotional needs and coping as FCs, while information needs were among the most highly reported needs. Marco et al. (2022) conducted a recent systematic review of reviews to identify the most reported FC's needs of people with advanced diseases, including cancer. The authors identified and arranged FC's needs according to their frequencies in the studies. Five most prevalent unmet needs that were reported in the selected reviews that involved: emotional support needs that entail HCPs' help and coaching in managing emotions, upset, and future uncertainty; illness-specific needs that incorporate information about the disease course and expectations; caregiver roles and responsibilities that involve robust education and information about how to provide care and the expectations of them as FCs; self-care practices and wellbeing needs that relate to the support that facilitates enhanced FC's quality of life and wellness, e.g. respite care; and lastly, support with practical tasks that involve FC's facilitated access for help with general daily living tasks, e.g.

shopping. This highlights that FC's needs are diverse, and their intensity could increase with advanced disease deteriorations that may involve more tasks and roles. However, if proper support was limited, these unmet needs would trigger several negative consequences (Girgis and Lambert, 2009).

Cancer caregiving has significant physical and psychosocial impacts on FCs (Harding et al., 2012). These impacts are closely related to the construct of **"Caregiving burden"**, the perception of the impact of caregiving tasks on the FC's physical, psychosocial, and financial aspects of their lives (Zarit et al., 1980). Burden is usually felt when FC's resources of support and personal coping are perceived as limited in relation to their caregiving needs (Pearlin et al., 1990, Bastawrous, 2013). Several studies explored caregiving outcomes and reported multiple FC's physical problems such as fatigue (Perpiñá-Galvañ et al., 2019), sleep disturbance (Maltby et al., 2017), low back pain, and reduced capacity for engagement in health-related activities, e.g., physical exercise (Girgis et al., 2012). This suggests that FCs experience a great deal of burden during caregiving, since they often ignore their self-care and wellbeing, resulting in sleep deprivation, physical inactivity, and unhealthy eating (Collins and Swartz, 2011, Dionne-Odom et al., 2017).

Family carers also experience several psychosocial impacts as a result of the caregiving process. In their study, Gotze et al. (2018) examined the psychological parameters; e.g. depression and anxiety, in 72 FCs of PwC in the palliative phase before and after the death of PwC;

they found that FCs experienced increased levels of depression and anxiety during caregiving. Furthermore, caregiving limits the FC's chances for socialisation with relatives and friends, which would trigger social isolation and loneliness. This is related to the difficulty in planning a head for social activities, such as, going in holidays, travel, hobbies, and outdoor socialisation with family and friends due to caregiving commitments (Girgis et al., 2012).

Additionally, caregiving negatively affects FC's education, employment, and financial status (Houses of Parliament, 2018). For example, increased care costs combined with limited employment hours or taking work leave to dedicate time to caring increase FC's financial burden (Gardiner et al., 2013). In an earlier Canadian longitudinal study of patients with breast cancer and their principal caregiver, Grunfeld et al. (2004) examined the psychosocial, occupational, and economic impacts of caring for a person with a terminal illness. The authors found that three-quarters of the employed FCs in the study missed work in the terminal period; FCs reported inability to work and losing many working hours to provide care in this period, which indicates that caregiving also impacts the social roles of FCs. Meanwhile, it is worth noting that the authors of the study found that caregiving negative outcomes increased at the start of the terminal period rather than the start of the palliative trajectory. This highlights that transitional events such as progressing into EoL increase FC's burden due to increased caring demands (Hauser and Kramer, 2004, Bijnsdorp et al., 2022).

By contrast, other studies reported the experiences of positive caregiving impacts such as a sense of personal growth and accomplishment of helping others in endurance, and self-worth (Girgis et al., 2012, Brown and Brown, 2014). Hudson (2004) interviewed 47 FCs who were previously took part in a trial assessing the efficacy of a psychoeducational intervention for FCs of PwC dying at home. They were asked to identify some positive aspects and challenges associated with their caregiving role as a part of the original study. FCs reported narratives that indicated experiencing several caregiving benefits, such as a sense of giving back to PwC, enjoying precious time with them, and an increased sense of self-sufficiency and personal growth. This suggests that a balanced view that considers the dual faces of family caregiving is worthy of note (Brown and Brown, 2014).

In the light of previous discussion of family caregiving impacts, various theoretical models exist for exploring family caregiving phenomena; however, they differ in their focus and perspective. For the purpose of this study exploration of such models was important to get an insight about the theoretical conceptualization of caregiving experiences. Therefore, the selection of the reported models was based on the dual interfaces of caregiving experiences, the negative interface of stress and burden and the positive interface of personal growth and reward. Some models, such as Pearlin et al. (1990) and Lazarus (1984), deal with caregiving as a stress-inducing phenomenon where individuals try to cope with this stress to continue their caregiving roles. For instance, Pearlin et al. (1990) caregiving stress process model that was developed

in dementia field identified four interrelated components that describe the caregiving process; contextual factors of caregiving (e.g. characteristics of FCs, family network and support availability); the caregiving stressors which were described as circumstance and caregiving issues that would create caregiver's stress (e.g. complex caregiving tasks and role conflict and strain); mediators or factors influencing the stress process which would minimise the impact of stressors (e.g. personal coping and social support provided either through family network or professionals); lastly, the outcomes dimension of the stress process model which reflects the physical and psychosocial impact of the caregiving process (e.g. anxiety and depression). Similarly, Lazarus (1984) transactional theory of stress and coping is widely used in exploring the caregiving process (Yuan et al., 2021). This theory identifies caregiving context as stress provoking where individuals engage in successive major processes that involve the cognitive appraisal process that helps to define the stress-inducing situation, its impact, and the available resources to deal with it; then individuals start a process of problem-focused coping to manage the source of stress and/or an emotion-focused coping to manage the emotional outcome of the process (Lazarus, 1984, Biggs et al., 2017, Yuan et al., 2021). Then, a reappraisal process of the situation occurs, which would result in another cycle of coping (Lazarus, 1984, Biggs et al., 2017, Yuan et al., 2021).

In another similar perspective, caregiving is perceived and dealt with as a life transition event that needs adaptation and coping to enable a successful transition (Schumacher et al., 2006). According to

“Transitions theory” (Meleis et al., 2000, Schumacher, 1994), FCs engage in a process of transition when a family member is diagnosed with a chronic illness that requires dedicated support and care from other members of the family; this would involve changes in their routines and future plans (Meleis et al., 2000). Two patterns of responses are expected to indicate healthy or unhealthy transitions. Firstly, responses that occur during the transition process such as, contacting HCPs and friends who would provide support; developing positive interactions with the PwC; being situated, i.e., life comparisons pre and during the caregiving that would enable FCs to explore new meanings of their lives; developing a sense of confidence and coping with the caregiving role. The second pattern of responses would appear later at the end of the transitional event (e.g., sense of mastery in being able to respond to PwC symptoms and practical care; identity fluidity in which FCs are able to maintain the balance of multiple identities such as FC, an employee, a spouse, and a mother) (Meleis et al., 2000). However, these patterns of response and transition outcomes are mediated by several factors that either facilitate or hinder a successful transition experience. These factors include personal factors (e.g., meanings attached to transition and knowledge and preparation); community conditions (e.g., family support and availability of community resources to facilitate transition, such as an information hub); and societal conditions (e.g., societal image for the transitional event, such as valuing FC’s contributions).

Although the previously mentioned models are useful for getting insight into the family caregiving process, they view caregiving as a

stressful event that would induce negative outcomes. The Transitions theory of Meleis et al. (2000) spotlights some potential positive responses that could be experienced during the caregiving transition process, such as developing confidence, enabling coping, and developing a sense of mastery; however, it is not clear the ultimate positive gains that would be experienced from the caregiving process. It could be argued that the focus of Transitions theory in the context of family caregiving would be more related to the outcomes throughout the transitional roles and tasks than to long lasting positive experiences of meaning making.

Nolan et al. (1995) highlighted the importance of considering the positive gains from the caregiving process, which could be either facilitated or hindered through the input of formal support (Nolan and Grant, 1989). Thereby, a theoretical model that focuses on the positive aspects of caregiving in dementia was developed by Carbonneau et al. (2010). They reported three related dimensions to explain the positive impacts of the caregiving experience. The model determines the factors that increase or decrease the likelihood of the positive role gains occurring (e.g. pleasant events , self-efficacy, sense of competence) ; the domains of positive aspects of caregiving that contribute to a beneficial experience (e.g., caring dyad's relationship quality, sense of achievement, meaning making in the caregiving role); and lasty, the potential positive outcomes of the caregiving process (e.g. enhanced FC's wellbeing and actualisation of their role). This model provided a framework for identifying the various positive rewards of the caregiving

process. However, it could be argued that the positive outcomes focused on physical and psychosocial wellbeing and role success with little focus on the long-lasting rewarding experiences.

Overall, these theories and models provide a comprehensive approach to exploring the caregiving phenomenon, however, some of them were developed in the dementia field (Pearlin et al., 1990, Carbonneau et al., 2010) which has a specific trajectory that differs from other chronic conditions such as cancer. This would suggest the need for a contextual-specific EoL cancer caregiving theoretical model to explain the caregiving dynamics in this context and provide guidance on the formal support strategies that would be offered (Penrod et al., 2012). Meanwhile, Oliveira (2017) argued that the current theoretical perspectives on caregiving explored the negative and positive caregiving dimensions separately, with more focus on the experience of care provision. This suggests the need for research that offers a more integrative view of caregiving phenomenon, which often involves both positive and negative aspects (Nijboer et al., 1998, Oliveira, 2017, Pope et al., 2018).

2.4. Palliative and end of life care

Structured modern approach to care for terminal-ill individuals in palliative phase flourished in the 1960s through UK hospice initiatives that were primarily aimed at PwC and depended mostly on charity funds (Higginson, 1997, Gray, 2011, Nathan, 2014). However, in 1980s the NHS started to contribute funding to support hospices and specialist palliative care initiatives (Higginson, 1997). Palliative care is described

by the World Health Organisation (2019) as an approach to care that enhances the quality of life of patients who face life-limiting illnesses, and their families, through the prevention and relief of their suffering. This is achieved through early identification and management of pain and other physical, psychosocial, and spiritual concerns, along with providing guidance and support to FCs during the patient's illness and bereavement (Sepúlveda et al., 2002). A comprehensive definition of palliative care was proposed by the Standing Medical Advisory Committee and Standing Nurse and Midwifery Advisory Committee (1992) which describes palliative care as;

"...active total care offered to a patient with a progressive disease and their family when it is recognised that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms within a framework of a co-ordinated service. Palliative care neither hastens nor postpones death, it provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of care. In addition it offers a support system to help relatives and friends cope during the patient's illness and in bereavement".

Palliative care practice is classified into generalised and specialist palliative care, the former involves the application of palliative care philosophy and relief of suffering into standard healthcare practice (Higginson, 1997, Twycross, 2021).This is achieved through the acquisition of basic palliative care knowledge and skills for all HCPs to deal with the most common palliative care needs of people with

progressive non curative illnesses (Gardiner et al., 2012, Quill and Abernethy, 2013). Specialist palliative care deals with more complex physical, psychosocial, and spiritual issues that requires extensive palliative care experience and skills that would facilitate specialised support for symptom management, care coordination, and consultation for general HCPs, patients, and families (Higginson, 1997, Twycross, 2021).

End of life care is usually used interchangeably with palliative care (Radbruch and Payne, 2009); however, it could be considered a part of palliative care that focuses on the care of a person in a terminal decline state (Wilcock, 2008) . EoLC is the care provided to people with terminal illness to enhance their quality of life until death, with a timeframe that ranges from a few hours or days to twelve months (Department of Health, 2008, General Medical Council, 2010, Gray, 2011). In the UK, EoLC has been the focus of policy development to ensure its effective delivery across all healthcare settings (Coventry et al., 2017). An EoLC strategy (Department of Health, 2008) was developed in the UK that represents a significant initiative for improving the practice of EoLC. It incorporates six pillars, considering the needs of people with terminal illnesses and their families' throughout EoL period (Department of Health, 2008, Calanzani et al., 2013, Coventry et al., 2017) (Figure 2.).

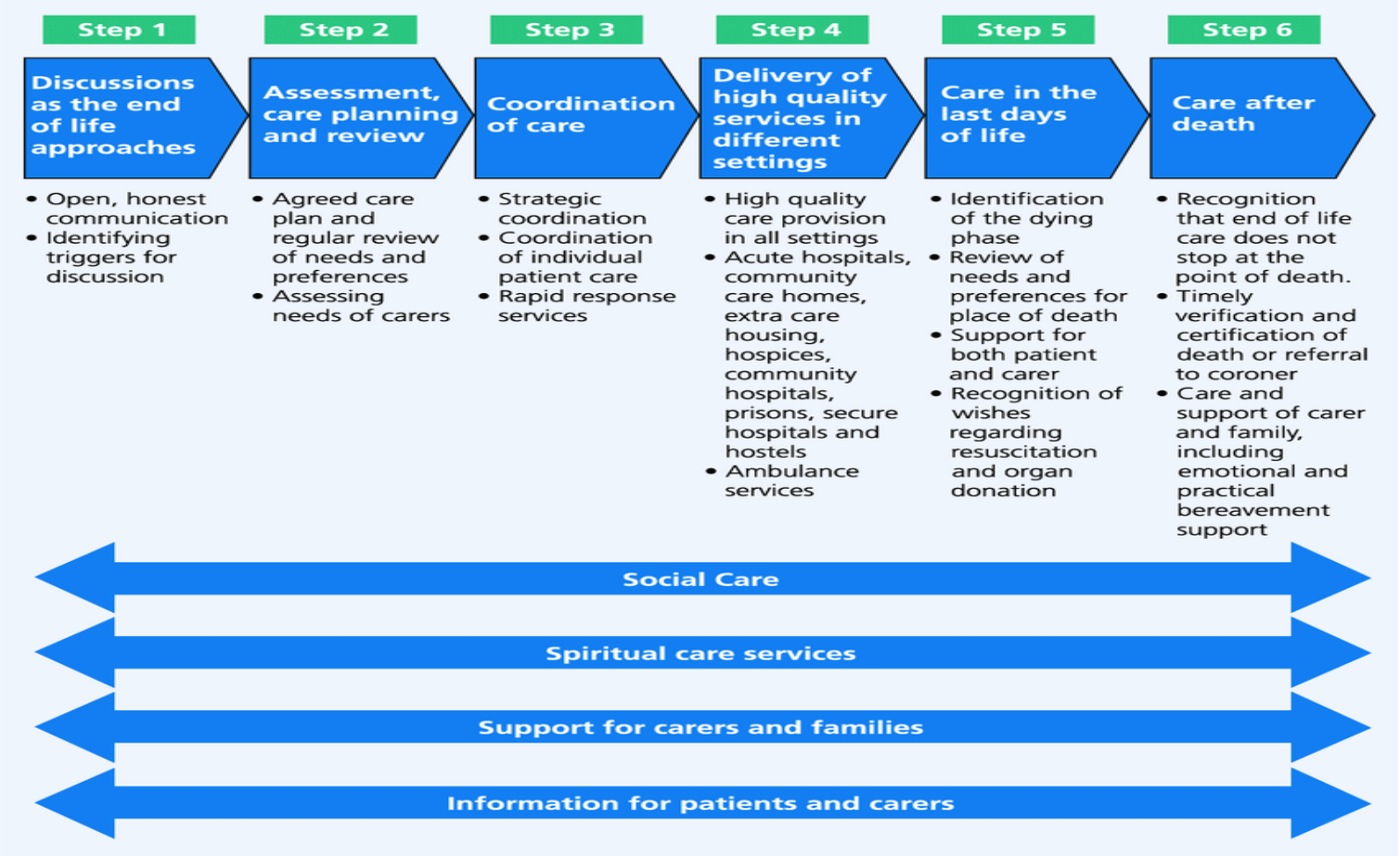


Figure 2. EoLC strategy (Department of Health, 2008, Calanzani et al., 2013)

This strategy had several strengths, such as comprehensive orientation, focusing on raising people's awareness, and professional development of HCPs; however, some challenges existed in its early application, such as varied service provision between localities (Gray, 2011). For instance, a national care of dying audit noted that only one fifth of the hospitals provided in-person specialist palliative care consultations seven days per week (Royal Collage of Physicians, 2014). This raises the concern of limited access to specialised services at times of need. Another challenge of EoLC strategy was its reliance on the ability of HCPs to establish meaningful relationships that facilitate EoL conversation and identify patient and family needs and preferences (Gray, 2011). This implies that if HCPs were not successful in developing such relationships, patient and their family needs might be overlooked. Similarly, the problems of accurate prognostication acted as a barrier to the timely initiation of EoL discussion and the provision of related services (Gray, 2011). This suggests that continuous EoLC service audits and research are important to adapt to the changing needs of society regarding this type of care and address its challenges with proper strategies.

End of life care is provided in a wide range of settings that include acute care (e.g., hospitals) and community care (e.g., hospices, care homes, and residential homes) (Department of Health, 2008). There is a worldwide assertion on the importance of providing care at the preferred place, with more emphasis on enabling people to die at home (Department of Health, 2008, Docherty et al., 2008, MacArtney et al.,

2016). In a bereavement survey study, Kinoshita et al. (2015) explored the association between place of death, quality of death and dying, and caregiver burden in terminally ill PwC and their families. The authors found that the place of death is an associate determinant for the experience of a good death in palliative care and EoLC, with a higher incidence in the home setting. The experience of a good death involves dying with dignity and respect in familiar surroundings, and supported by close family members and friends, which more typifies a home setting (Department of Health, 2008, Wahid et al., 2018). Thereby, most people would prefer to die at home if they were given the choice and adequate support was provided (Docherty et al., 2008, Department of Health, 2008, Shepperd et al., 2021).

Provision of EoLC at home would be more cost-effective than hospital care (Gomes et al., 2014, Wahid et al., 2018). However, there are other social costs, such as family caregiving time and community health services costs, that would make the cost-benefit of such care inconclusive (Gomes et al., 2014, Yu et al., 2015, Dixon Josie 2015). In their clinical review, Gomes et al. (2014) investigated whether home palliative care is associated with patients with advanced illness and FCs benefits and whether it is cost effective. They found that home palliative care is associated with increased incidence of home death and reduced symptoms in patients with advanced illnesses, with no change of FC's grief; however, they found that cost-effectiveness was inconclusive.

The quality of palliative and EoLC and palliative careof specialist services to foster comfortable care at home are significant determinants

that influence the decision to receive palliative care and EoLC at home and the achievement of home death (Gott, 2008, Bell et al., 2010, Seal et al., 2015). This is also mandated by the availability of FCs, the agreement between the caring dyad about the place of care (Thomas et al., 2004, Namba et al., 2007, Gysels and Higginson, 2009) and the impact of caregiving on FCs (Stajduhar and Davies, 2005). A national population-based survey in northern Ireland, Bannon et al. (2018) explored the factors associated with PwC achieving their wishes of home death. They found that receiving quality healthcare services at home and FC's preference for home death were among the factors that facilitated achieving home death. By contrast, limited community support combined with the care complexities at EoL and the limited availability of FCs could lead to admission at EoL (Seamark et al., 2014, Bainbridge and Seow, 2018, Shepperd et al., 2021). This highlights the importance of investment in improving and resourcing palliative and EoLC services to enable people to be cared for and die at their preferred place.

2.5. Family carers support at the end of life

In the previous discussion of family caregiving impacts in Section 2.3, it was concluded that FCs could experience a wide range of negative impacts as a result of family caregiving stressors. Thereby, exploring FC's support at EoL could be addressed from a generic perspective of social support in stressful events. House (1981) cited in Cooke et al. (1988) provided a comprehensive description of social support, which involves an interaction between individuals to provide one or more of the following, emotional concern through providing caring, love, and

empathy; instrumental aid through providing direct help, time, or money; information through guiding advice to cope with the situation; appraisal through providing informational feedback about coping. Cobb (1982) cited in Cooke et al. (1988) argued that support for subjective feelings would be achieved through four aspects that involve love, esteem, security, and appraisal. Compared to House (1981) definition, Cobb (1982) added security aspect that involves support received from being a part of a social group network. While it could be argued that this sense of security is an indirect part of the emotional support experience in House (1981) definition. Social support is further classified into the perceived support (i.e., subjective appraisal of support) and the actual interactions to provide help and support (Emerson et al., 2021, Faraci and Bottaro, 2022). Overall, the essence of supportive actions is helping others who are in need, which is classified widely into tangible, informational, and emotional, with the ultimate aim of improving the individual's wellbeing (Richman et al., 1993, Richmond et al., 2007).

In their seminal generic review about the typology of family care, Nolan et al. (1995) discussed FC's support levels more specifically and described it as a three-level continuum depending on the FC's engagement in the process of support. In other words, the support category is judged based on HCP's endeavours to involve FCs in the process of determining their support needs, while enabling them to contribute to the caregiving process. For instance, "**Facilitative support"** entails a systematic process of support provision at the time of need, which depends on the service provider's knowledge of the

caregiving process and FC's competence level. In this case, HCP's support is personalised according to the caring dyad's needs while helping FCs to be involved in the caregiving process according to their abilities. In the case of the second category "**Contributory support**" the support is provided in an unsystematic opportunistic way that supplements the FC's role; however, it occurs by chance and does not entail a careful judgement and negotiation process to provide personalised support as in the previous category. Lastly, **"Inhibitory or obstructive support"** refers to a support that is perceived as needed by FCs; however, if it contradicts with the caring dyad's support preferences, it will lead to an unsatisfactory experience and the discontinuation of support interaction. For instance, if HCPs restricted FC's engagement during care visits, the service would have been perceived as less satisfactory and might have been refused. This is because it has hindered the FC's opportunity for a reconstructive and reciprocal relationship with the person cared for through engagement in the caregiving process.

The traditional view of FC as a resource made the support initiatives mainly focus on practical support needs and the physical aspect of caregiving, with the ultimate aim of continuing FC's role (Twigg, 1994, Nolan, 2001). However, Nolan (1996) recommended that support should empower FCs to acquire the necessary skills to care without jeopardising their health and wellbeing. This could be achieved through a skilled assessment of caregiving determinants that involve caring demands, coping abilities, resources available, the perceived quality of

caring dyad relationships, and the perceived caregiving rewards (Nolan, 1996). Thereby, support offered would be individualised to FC's situations while considering the dynamic nature of the caregiving process and its related support needs (Nolan, 2001).

Caregiving for PwC at EoL at home constitutes a new facet of FC's experience, even for those who have provided caregiving for several years, due to the complexity of EoL care demands for which FCs are usually not prepared (Wilkinson and Lynn, 2005, Alvariza et al., 2020). Therefore, formal support is claimed to be essential for facilitating FC's coping and maintaining their wellbeing and quality of life (Wilkinson and Lynn, 2005, Gilbert et al., 2010). In a review by Stajduhar et al. (2010) exploring home-based family caregiving at EoL, it was reported that FC's supportive services could improve their quality of life, reducing their caregiving burden and contributing to better bereavement coping. Using an Australian population-based survey questions, Abernethy et al. (2008) evaluated the association between specialised palliative care services and short and long-term caregiver outcomes. They reported that many FCs had fewer unmet needs, e.g., practical care and respite; and had an increased ability to carry on with their lives after death when these services were involved.

Meanwhile, various FC's supportive interventions have been developed and tested in research (Uceda-Torres et al., 2016, Alam et al., 2020). In their meta-analysis of randomised trials of supportive interventions of FCs of PwC, Northouse et al. (2010) classified FC's support interventions into: psychoeducational interventions, which

involve providing information regarding caregiving aspects, disease management, caring dyad's relationships, and emotional needs; skills training interventions, which focus on the development of coping and problem-solving skills and behaviour modification in response to caregiving roles; and therapeutic counselling, which involves dealing with the emotional issues regarding the disease and associated caregiving challenges. This meta-analysis concluded that these interventions greatly reduced caregiver burden, and enhanced FC's coping, self-efficacy, and quality of life.

Similarly, regulations and healthcare guidelines describe strategies that enhance FCs' support. For instance, a recent National Institute for Health and Care Excellence (NICE) guideline (2020) highlighted recommendations for HCPs regarding FC's support (Figure 3.).

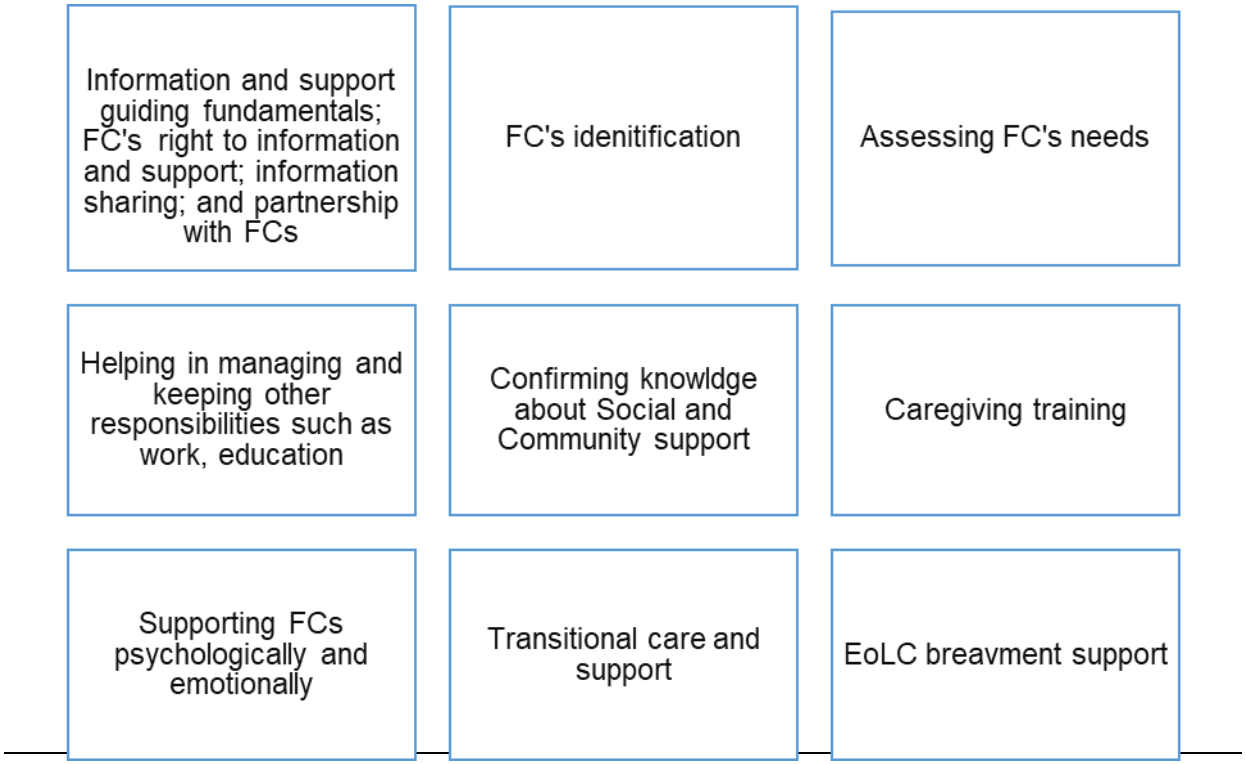


Figure 3. NICE recommendations for family carers support (NICE, 2020)

These recommendations provide a comprehensive approach for supporting FCs and addressing their unmet needs for information, practical help, and emotional wellbeing, which were discussed earlier in Section 2.3. In their systematic review of reviews about FC's needs in advanced disease, including cancer, Marco et al. (2022) reported four FC's preferred support provision approaches that included: direct service provision by HCPs (e.g., equipment provision, respite, counselling); communication with HCPs regarding prognosis, self-care, and emotional needs; direct education and practical training (e.g., caregiving responsibilities, medication management); and support through local community services and resources (e.g., social and emotional support). Although support strategies are well documented and EoLC services exist, FCs still experience unmet needs for support. In a recent integrative literature review, Kim and Baek (2022) explored the caring experiences of FCs of patients with pancreatic cancer, and they reported problems regarding information provision, emotional wellbeing, and FC's coping. Exploring the experiences of FCs with formal support is an essential aspect of EoLC service's evaluation (Gonella et al., 2019), since this would provide more explanation of the reasons behind FC's unmet support needs and suggest useful practice recommendations. In the next chapter, a qualitative narrative review will be presented that explores the experiences of FCs of PwC receiving home-based EoLC services.

2.6. Chapter summary

This chapter set the scene for this Ph.D. thesis; it provided an overview of cancer disease and its trajectory. It also discussed different aspects of caregiving phenomenon such as caregiving conceptualizations, FC's roles, needs, and the impacts of caregiving. It also presented different theoretical models of caregiving. This chapter highlighted the palliative and EoLC approaches, and it concluded by discussing the notion of FC's support initiatives.

CHAPTER THREE: QUALITATIVE NARRATIVE REVIEW.

3.1. Chapter introduction

This chapter discusses a qualitative narrative review on the experiences of formal support of FCs of PwC at EoL. It explores the state of research in this area, highlights research gaps, and provides a direction for future research. The chapter also discusses the justification for the present study and concludes by stating the study aim, and objectives.

Qualitative narrative review is a comprehensive approach to synthesizing various studies' findings into one document through well-established, reproducible, and non-biased methods to summarise and critically evaluate existing literature (Grant and Booth, 2009, Bearman and Dawson, 2013, Seers, 2015). One of the purposes of the qualitative review is to provide an understanding of research participants' experiences and perceptions (formal support experiences in this study) to provide good quality recommendations for healthcare practice based on reliable evidence and provide direction for future research (Bearman and Dawson, 2013, Lockwood et al., 2020).

The review of literature in grounded theory research; the methodological approach that was selected for the empirical phase of this study, which will be explored in the next chapter; is subjected to debate. Glaser (1967) advised delaying the literature review until developing the theory to avoid preconceptions and bias. While, Charmaz (2014) argued that that was not necessary because researchers should have been exposed to the literature to acquire the necessary knowledge

in any field. Therefore, there is no risk for bias if the researcher developed the orientation of the literature and theories while making endeavours not to enforce the data on them later on (Alemu et al., 2017). Furthermore, reviewing literature also helps the researcher develop theoretical sensitivity and guide the development of the research question (Charmaz, 2014, Rieger, 2019). In light of this discussion, Charmaz (2014) view was adopted for this study, since reviewing the literature was necessary for identifying the research gaps and providing a justification for this PhD study. Thereby, a comprehensive qualitative literature review using a narrative approach was conducted.

3.2. Aim of the review

This review explored the experiences of FCs of PwC receiving home-based EoLC services.

3.3. Review methods

A qualitative narrative review was conducted following Economic and Social Research Council (ESRC) guidelines for narrative synthesis (Popay et al., 2006). This approach was found useful for the present PhD for several reasons. It depends on approaching the literature in a systematic way, using robust search strategy, and using evaluation tools to critically appraise the current evidence (Popay et al., 2006). This facilitated citing the most relevant studies and identifying their strengths and weakness which shaped the design of current PhD study. Furthermore, this approach provides a systematic way for evidence synthesis that is based on using texts to summarise and combine the findings of different qualitative designs in a story telling fashion that would

help to identify and explain the research gaps (Popay et al., 2006). This method of narrative synthesis was primarily developed for exploring interventions effectiveness and implementation; however, the authors declared that it can be used in other types of reviews e.g., qualitative reviews exploring needs of particular population or their experiences as the case of this review (Popay et al., 2006, Nathan, 2014).

The narrative synthesis process (Popay et al., 2006) consists of four steps that involve developing a theory of how the intervention works, why and for whom. However, this step was not perceived necessary because this review neither explored an intervention effectiveness/implementation nor developing a theory/framework. The second step involves, developing a preliminary synthesis of the findings of included studies through an initial description and categorization of studies' findings (Popay et al., 2006, Nathan, 2014). This was done using narrative synthesis tools such as textual descriptions of studies, tabulation and translating data from one study to another using thematic analysis technique which will be explored further in Section 3.3.3. A third step involved exploring relationships between the findings of included studies and identifying the patterns and nuances across the studies' findings. In this review, this was done by conceptual mapping which refers to identifying similar findings in different studies and categorized them together while illustrating the relationship and link between them through diagrams (Popay et al., 2006). The last step involves assessing the robustness of the synthesis which was done through a critical reflection and discussion of the quality of evidence used, the review

process strengths and limitations and any sources of bias that could have influenced the credibility and transferability of the review findings (Section 3.5.2.) (Popay et al., 2006). The quality assessment of the included studies which was done early in the review process after studies' selection facilitated this process of reflection regarding the review robustness as well as determining the possible recommendations for future research (Higgins et al., 2008, Carroll and Booth, 2015). Studies were assessed by using the Critical Appraisal Skills Programme Qualitative Studies Checklist (Critical Appraisal Skills Programme (CASP), 2018). In their study about practical application of CASP tool, Long et al. (2020) contended that this tool is user friendly and suitable for novice qualitative researchers; it included points of what to consider in each question. The authors also alluded that tool is recommended by WHO and Cochrane for qualitative evidence synthesis process and has been widely used to assess health and social care qualitative research. For these reasons, CASP tool was considered appropriate for the context of this review and was adopted for the quality appraisal of selected studies. CASP tool involves ten questions to evaluate the credibility and trustworthiness of qualitative studies (Figure 4.).

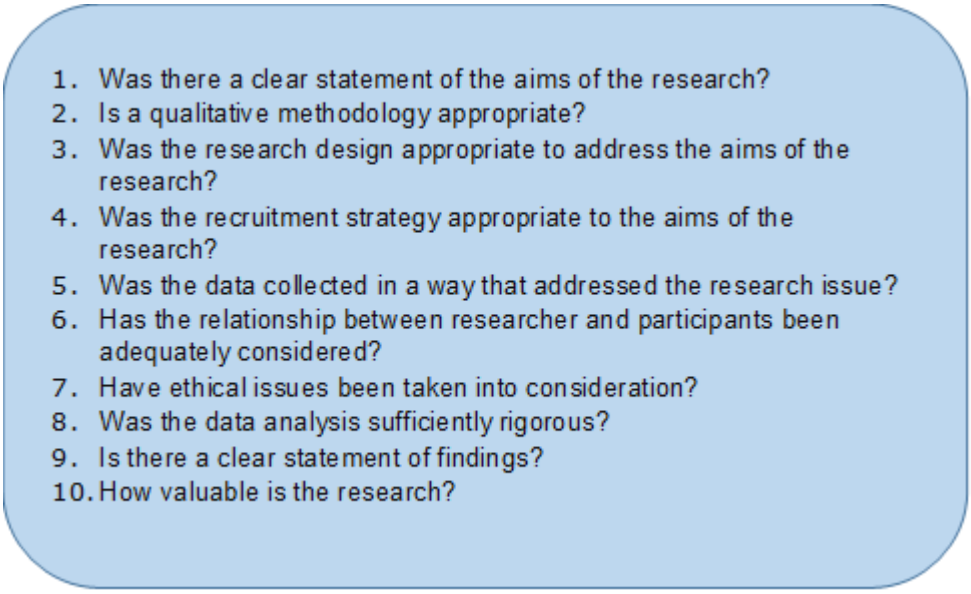


Figure 4. Critical Appraisal Skills Programme Qualitative Studies Checklist (Critical Appraisal Skills Programme (CASP), 2018)

The responses to CASP tool questions are either yes, no or can't tell. The scoring system ranges between (1) for yes responses and (0) for no or can't tell responses. There is not a definite overall scoring criteria associated with the CASP guidelines. However, Kanavaki et al. (2016) suggested an overall scoring system which was used in this review to determine the general quality of the studies. This scoring system classifies studies as high quality if they scored eight to ten; medium quality if they scored five to seven and low quality if they scored four or less. However, it was not intended to exclude any of the studies due to their quality.

Prior conducting the review, a preliminary search of the International Prospective Register of Systematic Reviews (PROSPERO) (Centre for Reviews and Dissemination University of York, 2018) was

conducted to establish if there were any previous or on-going reviews investigating the same review question. Two reviews were identified; Larsson et al (2016) investigated the preferences of FCs' support when caring for a family member at EoL at home but it did not address all aspects of the current review question, being general in scope and did not focus on cancer related experience. Another review was found that investigated home-based family caregiving at EoL but included all health conditions and did not focus solely on FCs' support (Funk et al., 2010).

3.3.1. Literature search and studies selection process

An initial scoping search was conducted by a single researcher to find out the keywords for major concepts of the review question, synonyms, MeSH terms through ProQuest thesauruses database, Medline, CINAHL, and Scopus. A further detailed search was conducted using the developed search strategy (Appendix 1.) according to studies inclusion criteria (Table 1.). The search was done without a date limit in Jan 2019, and it was updated in July 2020 through the following databases: CINAHL hosted in (EBSCO), Psych INFO hosted in (OVID), Applied Social Sciences Index and Abstracts (ASSIA) hosted in (ProQuest) and PubMed. These databases were nominated because they focus on health and psychosocial related studies which was suitable for the scope of this review. Then, the references of the selected studies were manually screened for relevant articles.

Table 1: Narrative review studies inclusion Criteria

- Studies focused on FCs of adult PwC.
- Studies discussed FCs' experiences of home-based EoLC services and the impact of the support of these services provided to FCs.
- Studies reported support services provided in home setting.
- Primary empirical peer-reviewed qualitative or MMR studies with a qualitative component in the English language with no restriction to origin or publication date.

Endnote® software for referencing was used for managing studies' records. Screening of the titles and abstracts was done, and articles did not meet inclusion criteria were excluded. The full text of potentially relevant articles was read in full and non-relevant ones were excluded. However, each step was consulted with the supervisory team and the selected articles were discussed with them regarding the inclusion criteria as a peer-debriefing strategy. PRISMA flow diagram was developed to illustrate the studies' selection process (Figure 5.).

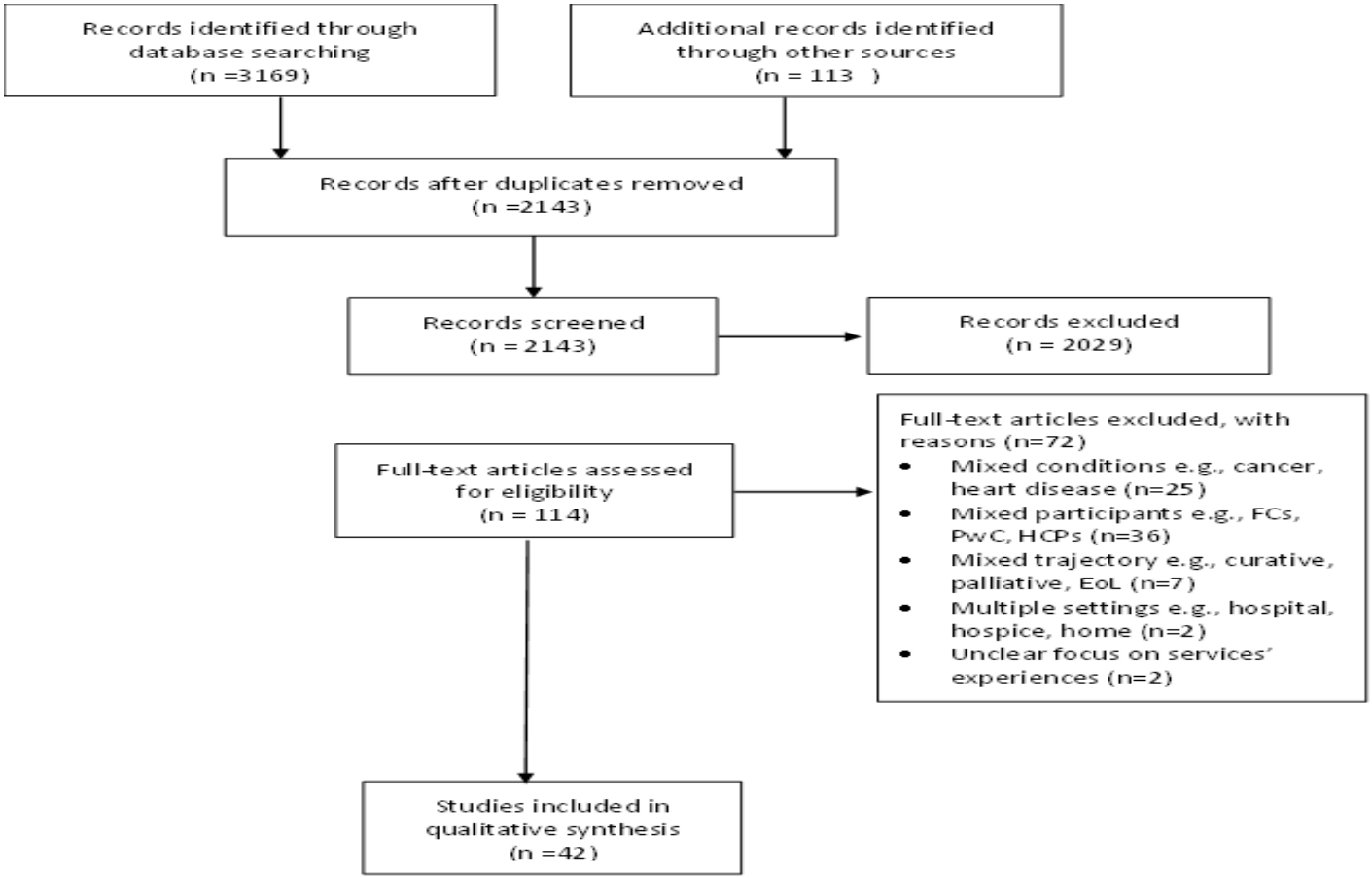


Figure 5. PRISMA flow diagram for the study selection process.

It was intended that authors of the selected articles would be contacted for missing information if needed. Literature search resulted in total of 2143 records after deduplication. 2029 records were excluded from the titles and abstracts. 114 records qualified for full-text review. 72 full-text articles were excluded mainly for including mixed patients' conditions e.g., cancer and heart disease (n=25), mixed participants' experiences e.g., FCs with PwC or HCPs (n=36), Mixed cancer trajectory e.g., curative, palliative and EoL (n=7), multiple setting experiences e.g., hospital, hospice, and home (n=2), unclear focus on services' experiences (n=2). 42 full-text articles were eligible for the quality appraisal process.

3.3.2. Critical appraisal of the reviewed studies

Critical appraisal process using the CASP tool illustrated that the majority of studies were rated as high quality while six studies were rated as medium quality (Appendix 2.). Overall, the general aim of the studies focused on describing FCs' needs, expectations, experience, and the impact of family caregiving as well as services' evaluation. However, more than half of the studies did not aim primarily for exploring the formal support experiences and only one study did not make their aim explicit (Aranda and Peerson, 2001). Majority of the studies used a generic qualitative paradigm without using a defined methodological framework that guided the research design and process. This resulted in a limited number of studies that explored FC's formal support through a methodological paradigm that contributed to the development of

theoretical models which could be used to explain and improve healthcare support practice.

The quality appraisal identified that methods' justification and reflexivity were the main methodological issues that were poorly reported in the studies (Aranda and Peerson, 2001, Dumont et al., 2008, Brazil et al., 2010, Chapple et al., 2011, Epiphaniou et al., 2012). This hindered identifying personal and professional biases that could have impacted the credibility of the studies' findings (Mays and Pope, 2000). Furthermore, lack of methodological justification made the research conduct process unclear which could risk establishing the trustworthiness of the studies' findings (Cohen and Crabtree 2006). However, this could be rationalized by the limitation imposed by publishers' word limits; therefore, these aspects were not clear (Blignault and Ritchie, 2009).

Two studies did not provide enough details on the process of participants' recruitment (Hudson, 2004, Brazil et al., 2010). Other studies did not explore ethical issues in data collection exhaustively such as not reporting about the ethics approval for their studies or how they handled consenting and data anonymity issues (Grbich et al., 2001, Luijkx and Schols, 2009). Some studies did not provide enough details on the actual implementation of the data analysis process such as how categories or themes have been identified (Rose, 1999, Hudson, 2004, Luijkx and Schols, 2009, Robinson et al., 2017, Spelten et al., 2019). This lack of clarity regarding the discussion of data collection and analysis could hinder making precise judgment about the transferability of findings

and developing trustworthiness in data interpretation (Mays and Pope, 2000).

Cohen and Crabtree (2008) argue that a comprehensive account of the participants' experiences should be supported by proper narratives to ensure the credibility of the qualitative report and conclusions. However, one study in this review (Hudson, 2004) was a part of a trial in which the qualitative findings lacked enough detail, and all quotations were grouped together in a table, which limited the contextual nature of the qualitative exploration. In some instances, there was a lack of evidence from participants' narratives to support the authors interpretations (Milberg and Strang, 2004), while, other authors did not discuss research implications of their studies to further enhance the caregiving research field (BrobÄCk and BerterÖ, 2003, Brazil et al., 2010)

3.3.3. Data extraction, analysis, and synthesis

Following the screening process, a preliminary synthesis through textual description of the studies and standardized tabulation of extracted data was done. A data extraction table was developed to suffice the purpose of this review. The decision for not using a standardized data extraction table was perceived appropriate. This is because, standardized data extraction could include unnecessary categories of information to the review purpose as well as it could be difficult to apply it to all types of included studies. Thus, a data extraction table was designed that included relevant information about authorship and year of publication, study country, aim, design, sample size, data collection and

analysis methods, main findings/themes, and any comments. Thematic analysis strategy was used as a tool for narrative synthesis (Figure 6.) for coding and developing the themes inductively using (Nvivo 12.0) and manual coding techniques. This was suitable for developing a thematic framework that captured the similar patterns across the studies rather than adopting a pre-defined framework. It also provided an opportunity for training on inductive qualitative analysis preparing for the empirical stage of the PhD study. However, the analysis was conducted in a descriptive level, since producing further interpretations or re-analysing the primary data of the studies was not required at this stage and the main goal of this review was to identify the research gaps.

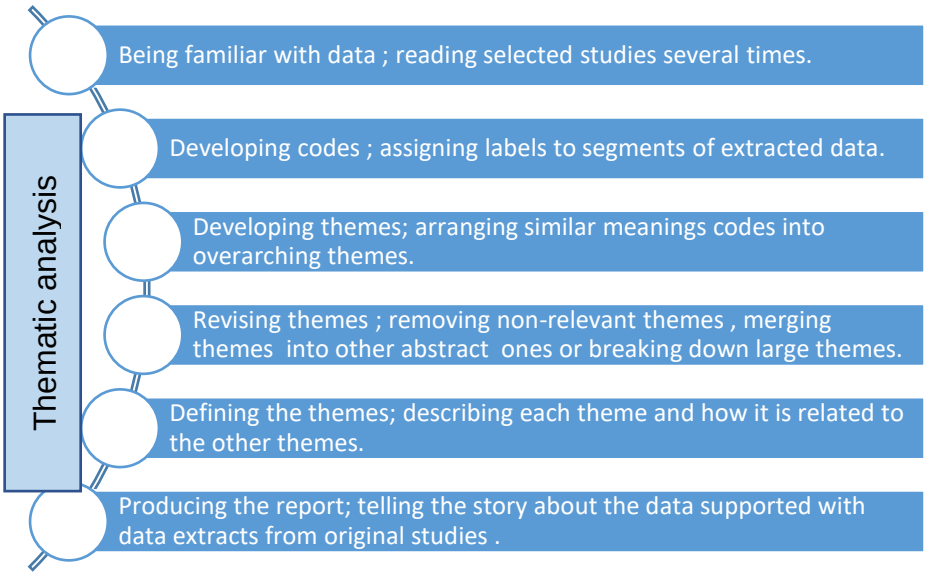


Figure 6.Thematic analysis (Braun and Clarke, 2006)

Additionally, conceptual modelling helped identifying relationships between themes that led to the development of the conceptual framework that described the narrative synthesis findings (Figure 7.). In extracting qualitative data from the selected studies, the Thomas and Harden (2008) approach for qualitative data extraction was adopted, extracting both the participants quotes and the authors' interpretations as a possible findings. This was perceived appropriate for capturing a comprehensive view of the FCs' experiences of formal support and it also resolved the dilemma of varied reporting styles in the studies (Thomas and Harden, 2008).

3.4. Results

Results are arranged in two sections that describe the characteristics of the studies and the synthesis of the qualitative findings to identify areas that would need further exploration in this PhD study.

3.4.1. Characteristics of studies

The vast majority of the included studies were conducted in western high-income countries such as UK (Table 2.)(Rose, 1999, Exley and Tyrer, 2005, Chapple et al., 2011, Richards et al., 2011, Epiphaniou et al., 2012, Harding et al., 2012, Johnston et al., 2012, Arber et al., 2013, Lovatt et al., 2015, Seal et al., 2015, McCaughan et al., 2019, Totman et al., 2015), Canada (Strang and Koop, 2003, Stajduhar et al., 2008, Dumont et al., 2008, Brazil et al., 2010, Maddalena et al., 2010, Duggleby et al., 2011, Ward-Griffin et al., 2012, Nielsen et al., 2013, Robinson et al., 2017, Shan et al., 2018), and Sweden (Andershed and Ternestedt, 1998, Wennman-Larsen and Tishelman, 2002, BrobÄCk and BerterÖ, 2003, Milberg and Strang, 2004, Holmberg, 2006b, Holmberg, 2006a, Linderholm and Friedrichsen, 2010, Klarare et al., 2017). It was apparent that the dominant research approach was the generic qualitative approach and mostly authors used qualitative interview as the main data collection method (Miranda do Vale et al., 2019, Oosterveld-Vlug et al., 2019, McCaughan et al., 2019, Spelten et al., 2019, Opsomer et al., 2019, Røen et al., 2018, Robinson et al., 2017, Lovatt et al., 2015, Totman et al., 2015, Lee et al., 2014, Johnston et al., 2012, Harding et al., 2012, Epiphaniou et al., 2012, Richards et al., 2011, Chapple et al., 2011, Sekelja et al., 2010, Brazil et al., 2010, Stajduhar et al., 2008, Dumont et al., 2008, Exley and Tyrer, 2005, Hudson, 2004, Strang and Koop, 2003, Wennman-Larsen and Tishelman, 2002, Aranda and Peerson, 2001, Rose, 1999, Andershed and Ternestedt, 1998). Thematic analysis used mostly for data analysis in the reviewed studies (Opsomer et al., 2019, Oosterveld-Vlug et al., 2019, Miranda do Vale et

al., 2019, Klarare et al., 2017, Ward-Griffin et al., 2012, Harding et al., 2012, Epiphaniou et al., 2012, Richards et al., 2011, Chapple et al., 2011, Maddalena et al., 2010, Stajduhar et al., 2008, Hudson, 2004, Strang and Koop, 2003, Grbich et al., 2001, Aranda and Peerson, 2001). Most of the studies adopted a cross-sectional approach that explored the phenomena at one point in time, while only one study used a longitudinal approach (Grbich et al., 2001). The majority of studies ultimately depended on bereaved FCs' accounts, while only three studies included experiences of both current and bereaved FCs (Røen et al., 2018, Grbich et al., 2001, Rose, 1999). Sample size in the majority of studies were relatively small that ranged from one case study (Holmberg, 2006a) to 61 participants (Shan et al., 2018) with a total of 746 FCs.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
1. Andershed and Ternestedt 1998 Sweden.	Generic qualitative interview study.	Increase existing knowledge about the involvement of relatives in care of the dying and to shed light on the relatives' sense of coherence. An additional aim was to shed light on the relatives' sense of coherence.	6 Relatives of patients with grave, incurable cancer.	Inductive and deductive analysis.	(1) Involvement of the Relatives in the Care and Their Sense of Coherence-Surgical Ward. (2) Involvement of the Relatives in the Care and Sense of Coherence-At Home. (3) Involvement of the Relatives in the Care and Sense of Coherence: Inpatient Hospice Ward and Nursing Home.
2. Aranda and Peerson 2001 Australia.	Generic qualitative interview study.	Explore Experiences of and effects on lay carers of providing palliative care to a person at home.	25 Lay caregivers of patients with advanced cancer.	Thematic and content analysis.	(1) Who decides and decision type. (2) Being able to provide care.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
3. Arber et al., 2013 UK.	Constructivist grounded theory using interview.	Explore the experience of family caregivers when caring for a person with a primary malignant brain tumour.	22 Primary current carers.	Constructivist grounded theory.	(1) Building helpful relationships. (2) Safe places and comfort zones. (3) Threats to connecting.
4. Brazil et al., 2010 Canada.	Generic qualitative interview study.	To examine how the Stress Process Model could elucidate on the stressors associated with caring for a palliative cancer patient and on the resources informal caregivers rely on to moderate the negative effects of caregiving.	12 Bereaved family caregivers of cancer patients.	Framework and inductive analysis. Constant comparative method.	(1) Primary stressor; care recipient symptoms and personal care needs. (2) Secondary stressors; health care delivery, financial and work-related stress, family conflict. (3) Resources; caregiver skills, informal support, health care delivery, (4) Outcome; caregiver experience.
5. BrobÄCk and BerterÖ 2003 Sweden.	Phenomenology using interview.	Identify and describe the next of kin's experiences of palliative care in the home.	6 Current next of kin carer to a cancer patient receiving palliative care at home.	Giorgi's phenomenological analysis.	(1) Adjustment. (2) Awareness. (3) Being perceived as a person. (4) Emotional effects. (5) Feeling of uncertainty. (6) Feeling insufficiency.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
6. Chapple et al., 2011 UK.	Generic qualitative interview study.	Explore why some of these patients reported a preference for end-of-life care and death either at home, hospice, nursing home or hospital, how strongly they felt about this, and how they described making decisions.	8 Patients of pancreatic cancer & 8 bereaved relatives who discussed the place of death (from a total sample of 32 people with pancreatic cancer and eight relatives of others who had died of pancreatic cancer.	An interpretive approach was taken, combining thematic analysis with constant comparison.	(1) Care available at home. (2) Experiences of hospital care. (3) Perceptions and experience of hospice care. (4) Fears of negative associations with the place of death.
7. Duggleby et al., 2011 Canada.	Grounded theory Using interview and focus group.	Explore the context or conditions under which older rural palliative care patients and their families experience transitions.	28 Participants 6 older rural persons with advanced cancer, 10 bereaved family caregivers and 12 rural healthcare professionals)	Thorne's Interpretive analysis.	(1) Community connectedness/isolation. (2) lack of accessibility to care. (3) Communication/information issues. (4) independence/dependence.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
8. Dumont et al., 2008 Canada.	Generic qualitative interview study.	Identify caregiving factors that are likely to influence the grieving process of family caregivers who provided care and assistance to a patient until his or her death.	18 Bereaved family caregivers of terminal cancer patient.	Content analysis.	(1) Characteristics of the family caregiver. (2) Patient characteristics. (3) Symptoms of the illness. (4) The relational context. (5) Social and professional support. (6) Circumstances surrounding the death.
9. Epiphaniou et al., 2012 UK.	Generic qualitative interview study.	Identify existing coping and support mechanisms among informal cancer caregivers in order to inform intervention development.	20 Current main family carer.	Thematic analysis.	(1) Coping mechanisms. (2) Caregivers sources of support.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
10. Exley and Tyrer, 2005 UK.	Generic qualitative interview study.	explore the views and experiences of bereaved carers of HAH services (it was a part of a pilot project for evaluation of HAH scheme in The East Midland).	12 Bereaved carers cared for people died from cancer.	Framework analysis.	(1) Reasons for choosing HAH. (2) Formal care. (3) Out-of-hours care. (4) Provision of specialist equipment.
11. Grbich et al., 2001 Australia.	Quantitative and qualitative (Naturalistic paradigm general) Qualitative part: -Focus group. -Longitudinal broad open-ended interviews.	Investigate, from the caregiver's perspective, the impact of caring for a person with a diagnosis of terminal cancer, in order to improve the delivery of home-based hospice services.	Qualitative part: 12 Bereaved family carers for the focus group attended a 16-week support group at the hospice. 20 Current family caregiver for longitudinal interview. 40 Key health professionals for the focus group.	Thematic analysis.	(1) Communication and information. (2) Emotional support. (3) Physical task support. (4) Caregiver health and wellbeing. (5) Financial needs.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
12. Harding et al., 2012 UK.	Cross-sectional Generic qualitative interview study.	Generate qualitative data that would give the required understanding of caregivers' specific support needs and the challenges to providing informal home care to a relative or friend with advanced cancer.	20 Current main family carer.	Thematic analysis.	(1) Caregivers' Unmet needs. (2) Challenges.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
13. Holmberg, 2006b Sweden.	Case study.	Describe and analyse the communication between a dying son and his mother in relation to the intervention by a palliative home care team.	One case study of a mother and her son diagnosed with cancer (2 main carers (mother and mother-in-law. Wife and one daughter, father, sister and brother, other friends.	-Document analysis of diary and notes on medication, nutrition, and care. Other documents were also used, such as letters to friends after her son's death and notes on the mother's experiences from meetings in bereavement groups. -Content analysis.	**First**, the narrative on the communication between the mother and her son. **Second**, the concepts of despair, hope, denial, belief, and control, emerging are discussed in a time perspective.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
14. Holmberg, 2006a Sweden.	Case study.	Examine the impact of verbal and nonverbal communication between family caregivers and a palliative home care team on the support given to family caregivers in palliative home care.	One case study of a mother and her son diagnosed with cancer (2 main carers (mother and mother-in-law. Wife and one daughter, father, sister and brother, other friends.	- Document analysis of a diary and collected notes. -Stepwise through content analysis.	(1) Communication in action. (2) The palliative care expands. (3) The formal multidisciplinary network. (4) The end of the palliative care.
15. Hudson, 2004 Australia.	Qualitative interviews as a part of Larger RCT.	Explore the challenges and positive aspects associated with supporting a relative or friend dying of cancer at home.	47 Current principal Lay caregiver of patients with cancer dying at home.	-Content and thematic analysis.	(1) Challenges associated with caring for a dying relative/ friend. (2) Positive aspect associated with caregiving.
16. Johnston et al., 2012 UK.	Generic qualitative interview study.	Understand patient and carer experiences of advanced cancer at end-of-life care and explore how patients care for themselves at the end of life.	A purposive sample of 20 patients with advanced cancer in the last year of life and their main carers and health professional involved in their care.	-Framework analysis.	(1) Maintaining normality. (2) Preparing for death. (3) Support—family/friends. (4) Self-care. strategies/physical. (5) Self-care strategies/emotional. (6) Support from healthcare professionals.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
17. Klarare et al., 2017 Sweden.	Narrative research using qualitative interviews inspired by the critical incident technique.	Investigate how the team's work is manifested in care episodes narrated by patients and families in specialized palliative home care (SPHC).	6 Patients with advanced malignant diagnosis receiving specialized home care and 7 family members.	-Thematic analysis.	(1) Security ("They are always available," "I get the help I need quickly"). (2) Continuity of care ("They know me/us, our whole situation and they really care").
18. Lee et al., 2014 Taiwan.	Longitudinal generic qualitative study using semi-structured interviews and observation.	Examine the family's experiences and needs over a 1-year data collection period in relation to the provision of hospice home care to the terminally ill elderly people with cancer in Taiwan.	44 Current family caregivers of elderly persons with advanced cancer and receiving home hospice care.	-Inductive content analysis.	(1) Hoping for a cure. (2) Experiencing fluctuating emotions. (3) Accepting the patient dying. (4) Regarding the patient's death as a good death (5) Needing emotional support and information.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
19. Linderholm and Friedrichsen, 2010 Sweden	Gadamer hermeneutic qualitative approach using semi-structured interviews.	Explore how the informal carer of dying relative, admitted to primary health care areas, experienced their caring role and support during the patient's final illness and after their death.	14 Bereaved family members of patients with cancer.	Hermeneutic analysis according to Gadamer	(1) Becoming a carer. (2) Being a carer. (3) Not being a carer anymore.
20. Lovatt et al., 2015 UK	Generic qualitative interview study	Explore the emotional labour undertaken by HCAs in community palliative care settings from the perspectives of both HCAs and family carers caring for cancer patients at home.	33 Bereaved carers of cancer patients and 8 health care assistants	-Grounded theory analysis.	(1) HCAs developing and maintaining relationships on the professional/personal boundary. (2) The ability of health care assistants to negotiate clinical/domestic boundaries in the home. (3) HCAs and family carers working together to enable the patient to die at home.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
21. Luijkx and Schols, 2009 Netherlands.	Four sequential studies using focus groups, a survey, individual interviews, and An Internet panel while only the qualitative focus group was used in the review.	Present the experiences of families of terminally ill patients with volunteer support.	Focus group with 22 Bereaved FCs from patients who received / not received volunteer support. Survey of 237 family members of terminally ill patients. Individual interviews with 6 FCs participated in the survey. Internet panel of 1712 people.	-The analysis method was not mentioned.	The results from the focus group illustrated that volunteers can make the last phase of life to be less stressful for family caregivers by offering practical and emotional support.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
22. Maddalena et al, 2010 Canada.	Case study using in-depth interviews.	Examine the meanings that African Canadians living in Nova Scotia, Canada, ascribe to their experiences with cancer, family caregiving and their use of complementary and alternative medicine (CAM) at end of life.	3 Primary bereaved carers of patient with cancer and 4 secondary carers.	-Thematic analysis and discourse analysis.	(a) Roles and expectations of caregivers. (b) Lack of knowledge of both the health system and the disease. (c) the importance of spirituality during their illness and death. (d) Complementary and alternative healing practices.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
23. McCaughan et al., 2019 UK.	Generic qualitative interview study incorporating 'Framework' analysis.	Explore the experiences and reflections of bereaved relatives of patients with leukaemia, lymphoma or myeloma, and examine (1) preferred place of care and death; (2) perceptions of factors influencing attainment of preferences; and (3) changes that could promote the achievement of preferences.	10 Main bereaved relatives.	-Framework analysis using a deductive approach.	(1) Preferred place of care and place of death. (2) Factors perceived to influence achievement of preferred place of care and death. (3) Suggested changes to facilitate care and death in the preferred place.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
24. Milberg and Strang, 2004 Sweden.	Hermeneutics using semi-structured interviews.	Describe and interpret the content of comprehensibility and manageability of cancer patients' informal carer in advanced palliative home care within Antonovsky's salutogenic framework of SOC.	19 Current adult informal carers of the patients with cancer.	-Hermeneutic analysis.	Results were presented in two ways; firstly it was presented in two major themes of the chosen framework of SOC. (1) Comprehensibility that was facilitated by; open information, symbolic information from the patient condition or symptoms or staff, basic life assumptions and previous knowledge. (2) Manageability that was enhanced by; the power of patient and self, competence of staff and family carers, accessibility to formal and informal support, the support provided. Then the results described the carers' experiences as a whole under the theme of togetherness/ isolation.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
25. Miranda do Vale et al., 2019 Brazil.	Generic qualitative descriptive interview study.	Know the self-care needs of family caregivers regarding the care of patients with palliative care at home and propose strategies to these caregivers for self-care.	10 Current family caregivers of cancer patients in homeopathic palliative care.	-Thematic content analysis	(1) Being a caregiver; overweight and quality of life. (2) The need for care of the other as an obstacle to one's care.
26. Mok et al., 2003 Hongkong.	Grounded theory using semi-structured interviews.	Describe the caregiving process and the impact of being the main caregiver for a terminally ill patient.	24 Primary bereaved caregiver of cancer patient.	-Constant comparison analysis.	(1) Precondition; Commitment in Caring, (2) Process of caregiving (3) consequences, (4) Influential factors in process of caregiving.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
27. Nielsen et al., 2013 Canada.	Focused ethnographies using interviews and observation.	Describe and examine how meanings of home condition negotiations of care for first-generation Chinese immigrants with advanced cancer receiving palliative home care, family caregivers, and home care providers.	11 Key informants in addition 4 cases (4 Chinese immigrant care recipients of palliative home care, 5 current primary family caregivers, and 3 home visiting nurses).	-Ethnographic analysis.	The results portrayed that palliative care was not perceived as an intrusion to the home and family life but an integration into the routines of the home where patient and family caregivers identified their need for palliative care providers to help navigate the health system and facilitate dying at home. Whereas, patient and family caregivers were not completely comfortable with having palliative care at home.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
28. Oosterveld-Vlug et al., 2019 Netherlands.	Generic qualitative interview study.	Get insight in the elements that patients with advanced cancer and relatives consider essential for high-quality palliative care, and whether these essentials are present in the actual care they receive.	13 Patients with advanced cancer and 14 relatives.	-Thematic analysis.	Six essential elements for good quality palliative care provided at home: (1) medical proficiency. (2) availability. (3) a focus on the person. (4) proactivity. (5) proper collaboration and information transfer between professionals. (6) clear and rapid procedures.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
29. Opsomer et al., 2019 Belgium.	Generic qualitative interview study using thematic analysis with an inductive approach	Explore what intrinsic and extrinsic resources facilitate or hamper resilience in the middle-aged partner of a patient with incurable cancer.	9 Principal caregivers of recently deceased middle-aged cancer Patients.	-Thematic analysis.	Two categories of facilitators of the resilient process. (1) Caregiver resources comprising four themes: sense of initiative, adaptive dependency, adaptive flexibility and positivism. (2) Context resources comprising three themes: availability, meaningful relationships and the patient's role.
30. Richards et al., 2011 UK.	Generic qualitative interview study.	Explore the experiences of people with advanced cancer and/or their caregivers accessing out-of-hours care.	13 Patients with advanced cancer and/or their 15 caregivers.	-Thematic analysis using the constant comparative technique	(1) Legitimacy of seeking help. (2) Continuities of care.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
31. Robinson et al., 2017 Canada.	Interpretive descriptive qualitative design using semi-structured interviews.	Describe the experiences of bereaved FCGs who were successful in providing their family members, who were terminally ill with advanced cancer, with a desired home death.	29 Bereaved FCGs.	-Constant comparison analysis.	(1) Context of providing care. (2) Supportive antecedents to providing care at home. (3) Determination to provide care at home. (4) Enabled determination.
32. Røen et al., 2018 Norway.	Qualitative exploratory design using semi-structured interviews.	Explore factors promoting carer resilience, based on carers' experiences with and preferences for health care provider support.	14 Carers of Advanced cancer patients.	-Systematic text condensation.	Four main resilience factors were identified: (1) being seen and known by health care providers—a personal relation. (2) Availability of palliative care. (3) information and communication about illness, prognosis, and death. (4) Facilitating a good carer–patient relation.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
33. Rose, 1999 UK.	Qualitative study using phenomenological tradition utilizing unstructured interviews.	Consider how far the experiences of the informal carers interviewed in the study confirmed or contradicted the findings of other researchers, and to consider what the experiences of those individuals can contribute to the development of nursing practice.	21 Carers of adult with cancer.	-Used literary theory and practice to identify recurring themes.	(1) The illness and information. (2) Information and prognosis. (3) Individual need. (4) The importance of sensitivity to need. (5) Information: whose right? (6) False information.
34. Seal et al., 2015 UK.	Qualitative narrative approach using interviews.	Understand family members' experiences of providing care for a loved one with cancer during the last phase of their life when those family members had been unable to fulfil their loved one's wish to die at home.	10 Bereaved family members of people with cancer.	-Narrative analysis.	(1) The cancer diagnosis. (2) The terminal stage and advancement of death. (3) Death itself. (4) Reflections on the whole experience.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
35. Sekelja et al., 2010 Australia.	Generic qualitative interview study.	Investigate how bereaved carers of cancer patients, experienced palliative care during the patient's illness and after the patient died, and to explore carers' subsequent preference for palliative care contact.	30 Main carers (lay and unpaid) of cancer patients participated in a randomised controlled trial (RCT).	-Interpretive phenomenological analysis (IPA)	(1) Meaning of palliative Care. (2) Extent of contact with palliative care services. (3) Preference on timing of palliative care. (4) Valued aspects of palliative. (5) end-of-life issues, preparation for patient's death and the role of palliative care.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
36. Shan et al., 2018 Canada.	Grounded theory using semi-structured interviews.	Describe bereaved caregivers' experiences of providing care at home for patients with advanced cancer, while interacting with home care services.	61 Bereaved caregivers of adults with advanced cancer who had participated in the trial.	Constant comparison approach.	A core category of taking charge was identified from the interviews that have four interrelated subcategories: (1) Navigating the system— navigating the complexities of the home care system to access resources and supports. (2) Engaging with professional caregivers—interacting with visiting personnel to advocate for consistency and quality of care. (3) Preparing for death—seeking out information about what to expect at the end of life. (4) Managing after death—managing multiple administrative responsibilities in the emotionally charged period following death.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
37. Spelten et al., 2019 Australia.	Generic qualitative interview study. Process data were included to describe the frequency and nature of contacts.	Describe the experience of families and nurses with extended rural palliative care to support dying at home.	10 Bereaved family carers, 4 nurses.	-Phenomenological approach -Deductive thematic analysis.	(1) Experience with the palliative care service. (2) The process of dying at home.
38. Stajduhar et al., 2008 Canada.	Interpretive descriptive qualitative approach using semi-structured interviews for the qualitative component of a mixed method study design.	Describe factors influencing family caregivers' ability to cope with providing such care.	29 Current family caregivers of adult with advanced cancer.	-Thematic analysis.	Caregivers' ability to cope was influenced by five factors arranged in the following themes: (1) The caregiver's approach to life. (2) The patient's illness experience. (3) The patient's recognition of the caregivers' contribution to his or her care. (4) The quality of the relationship between the caregiver and the dying person. (5) The caregiver's sense of security.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
39. Strang and Koop, 2003 Canada.	Exploratory, interpretative, and descriptive research orientation using interviews.	To present findings related to how caregivers coped while they cared for a dying family member at home.	15 Bereaved family caregivers to persons who had died of cancer.	-Thematic analysis.	Findings of the study reported factors that facilitate or interfere with caregiver coping in two themes; (1) Facilitating factors; caregivers' characteristics; dying persons' contributions; support from informal and formal sources. (2) Interfering factors: caregiver experiences with informal and formal systems of support.
40. Totman et al., 2015 UK.	Generic qualitative interview study.	Explore the emotional challenges faced by home caregivers, and their experiences of healthcare professionals, from the perspective of existential psychology.	15 Bereaved relatives of cancer patients.	-Framework analysis.	Carers experiences were organised according to Yalom's four 'existential conditions' (1) Responsibility. (2) Isolation. (3) Death. (4) Meaningfulness.

Table 2. Characteristics of studies

Author/year/country	Design	Aim	Participants	Data analysis	Main themes/results
41. Ward-Griffin et al., 2012 Canada.	Focused ethnography using semi-structured interviews and participant observations.	Explore the relational experiences among older adults with advanced cancer and their family caregivers and home care providers within the socio-cultural context of home-based end-of-life care.	4 Family members of older adults with advanced cancer.	-Inductive thematic analysis with comparing and contrasting of codes data.	Three categories of relational care experiences: (1) Prioritising care recipient needs–ignoring own needs. (2) Feeling connected–feeling isolated. (3) Juggling to manage–struggling to survive.
42. Wennman-Larsen and Tishelman, 2002 Sweden.	Generic qualitative interview study.	Prospectively explore how family caregivers reason about their expectations of providing end-of-life care at home for relatives with cancer, enrolled in advanced palliative home care units.	11 Primary family caregiver.	-Constant comparative analysis.	(1) Role transition in becoming a family caregiver. (2) Transition to a new life situation of the caregiver.

3.4.2. Review findings

This synthesis identified FCs' experiences of PwC receiving home-based EoLC services in three major themes (Figure 7.). The first theme discussed the experienced sources of EoLC support at home which included two categories of support: patient care support and FCs' wellbeing support. Secondly, the synthesis discussed the influencers of support experiences and care satisfaction which included the quality of relationships, responsiveness of service, HCPs' specialized knowledge and skills. Lastly, the third theme reported three impacts of support experiences that involved emotional wellbeing, coping with caregiving demands and trust in health care services and HCPs that were informed by the reception of the support sources and their lived experiences.

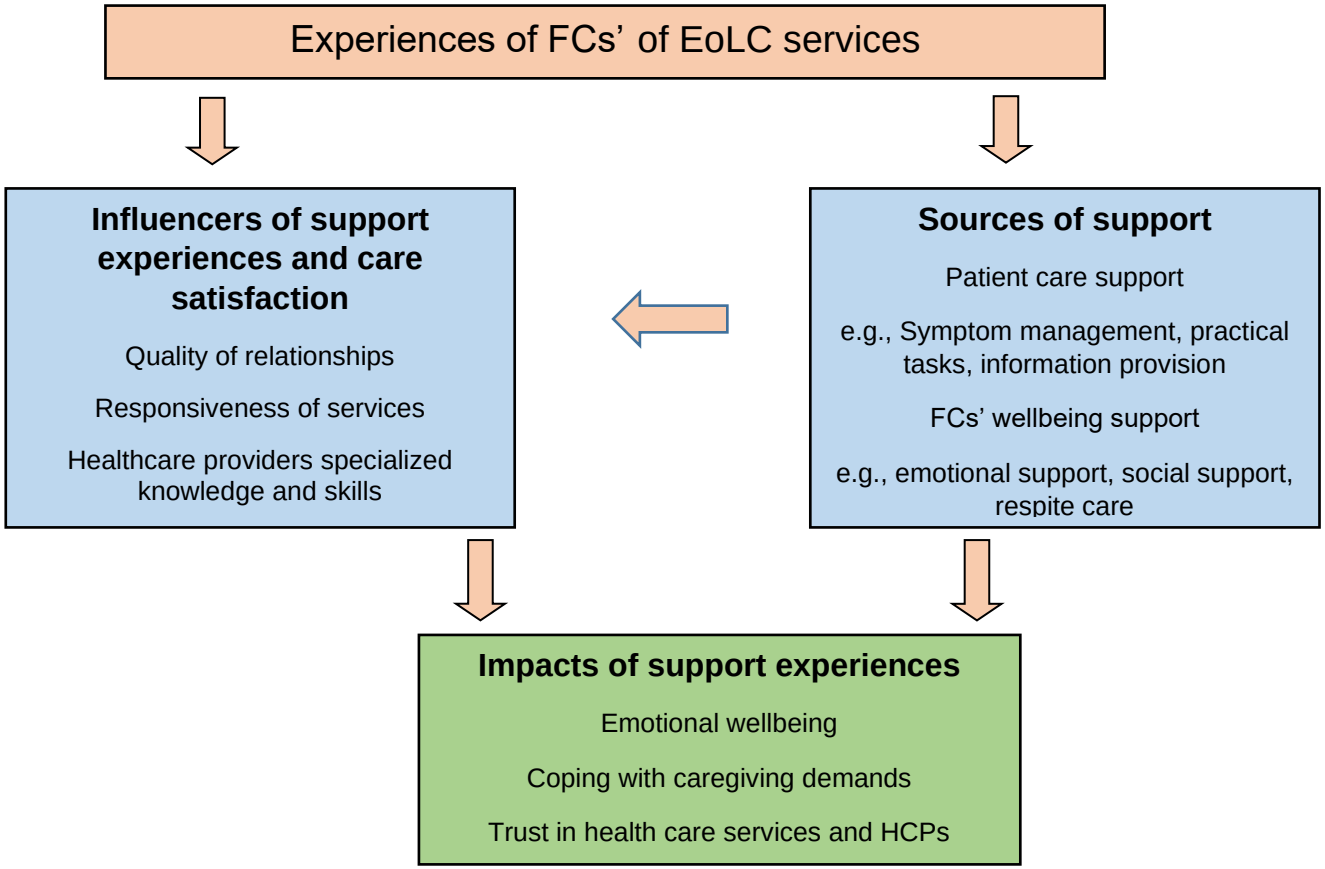


Figure 7. FCs' experiences of EoLC services

3.4.2.a. Sources of support

This review identified two major sources of support for FCs. Firstly, supportive services that mainly focused on PwC's care needs through helping FCs to deal with caregiving tasks e.g., symptom management and personal care. The second type of support was FCs' wellbeing support that is concerned with FCs' own needs and wellness such as emotional and social support and respite care. In the following sections these types of support will be explored in detail with illustrations from the original articles.

- Patient care support

Healthcare professionals offered several patient support interventions at home that promoted patient comfort and enhanced FCs' coping with caregiving tasks. This helped in relieving FCs' caregiving burden and had an indirect positive emotional impact on them. Studies highlighted that HCPs supported FCs in PwC's symptom management either by direct provision or administration of medication or training FCs in medication management for symptom control (Grbich et al., 2001, Wennman-Larsen and Tishelman, 2002, Mok et al., 2003, Milberg and Strang, 2004, Holmberg, 2006b, Shan et al., 2018, McCaughan et al., 2019, Spelten et al., 2019). This embraced FCs' emotional comfort and fostered their sense of confidence to provide the care for PwC (Grbich et al., 2001, Mok et al., 2003).

"The team assisted with symptom management, treatments, information regarding care options, organisation of equipment, and liaison with other services". (Grbich et al, 2001)

"The nurse taught me how to give the medications. How many tablets should my wife take? The information increased my confidence in looking after my wife. After following the instructions, my wife's condition improved, and her vomiting decreased (caregiver 5)". (Mok et al., 2003)

Figure 8.1. Studies extracts

However, this was noted as a problem in other studies due to limited access to this type of support during out of hours (Richards et al., 2011, Exley and Tyrer, 2005, Grbich et al., 2001). Exley and Tyrer (2005) explored the experiences of bereaved FCs of hospice at home services. They reported that FCs found difficulty in symptom management even with their training for this task which highlights the need for further exploration of other options that address this challenge of limitation of access to symptom management whenever needed.

"one carer was distressed by the lack of 24hour access to care when her father was in pain and no-one was present to relieve it …." (Carer 3)." (Exley and Tyrer , 2005)

"As part of the service, HAH nurses trained carers to administer drugs for pain control for times when they were not present because out-of-hours voluntary nurses were not trained to do this procedure. Some carers found this aspect of care difficult." (Exley and Tyrer , 2005)

Figure 8.2. Studies extracts

Another part of patient care support involved home adaptation and provision of the necessary equipment to make caregiving feasible and home environment suitable for EoLC (Grbich et al., 2001, Wennman-Larsen and Tishelman, 2002, Klarare et al., 2017, Robinson et al., 2017, Røen et al., 2018, McCaughan et al., 2019).

> *"Working solutions for the family to enable secure care at home. This entailed assessing the home environment and adapting care provision to suit the environment" (Klarare et al, 2017)*

Figure 8.3. Studies extracts

However, participants in other studies complained about delayed equipment delivery and removal (Grbich et al., 2001, Exley and Tyrer, 2005, Oosterveld-Vlug et al., 2019). For instance, Exley and Tyrer (2005) acknowledged that delayed access to supportive equipment led to delayed discharge to home. In another study exploring the experiences of providing care for PwC during EoL when dying at home was not fulfilled (Seal et al., 2015), the authors illustrated that equipment provided at home created a sense of intrusion and distress due to the medicalisation of the home environment. These mixed views about equipment provision and adaptation suggested that they were not always helpful for FCs' experiences if this happened against their preferences and/or invaded their personal space. This would suggest the need for further investigation to elaborate on the best practice for equipment provision at home.

'Getting the equipment together was a process that could have been done quicker and I would have had her home there and then if they had delivered the bed and the service was available. I would have had her home sooner, but I didn't know it was going to be 9 days' (Carer 7). (Exely and Tyrer, 2005)

"In order to facilitate a home death, the need for aids and adaptation to the physical environment may lead to the environment being altered beyond all recognition. Thus, the implication is that home is no longer home in the true sense of the word; rather, it becomes a substitute medical facility. "It's the fact that you're having a lot of intrusion into your house. You're having that balance thrown everywhere (. . .) and it won't feel like home anyway, to the person." (Seal et al, 2015)

Figure 8.4. Studies extracts

Other patient care support involved FCs' help with practical tasks. A study exploring the impact of caring for a person with a diagnosis of terminal cancer, noted that although the personal care support was in the care support backage , it was rarely used due to the patients' sense of embarrassment (Grbich et al., 2001). Similarly, FCs were offered washing services to support with the increased household washing due to patient incontinence; however, these services were unknown to some FCs in the same study (Grbich et al., 2001). Caregiving was described as labour intensive with respect to multiple practical tasks that FCs would be involved in, that would increase their burden. However, this review highlights the need for more evidence regarding the experiences of HCPs practical tasks support to provide a conclusive overview of

experience of type of support especially household tasks that is related to patient care.

"Hygiene needs varied from minimal assistance to full dependence. Although assistance was available ….. for help with hygiene, some caregivers preferred to provide that care if it was needed." (Grbich et al, 2001)

"Incontinence of both urine and faeces was another aspect caregivers had to manage. In some instances, this added further to physical strain because of the increase in the amount of washing. One caregiver found the linen service offered by SDCRS extremely valuable, but most other caregivers were not aware that this existed." (Grbich et al, 2001)

Figure 8.5. Studies extracts

Provision of information was another type of patient care support offered. FCs in this review received informational support about disease trajectory, treatment options, dying issues, practical caregiving skills and available supportive services (Grbich et al., 2001, Mok et al., 2003, Strang and Koop, 2003, Milberg and Strang, 2004, Exley and Tyrer, 2005, Holmberg, 2006b, Stajduhar et al., 2008, Sekelja et al., 2010, Lovatt et al., 2015, Røen et al., 2018, Shan et al., 2018, McCaughan et al., 2019). This helped them to be more prepared, reassured and able to move smoothly through their journey of EoL cancer caregiving as well as cope with bereavement (Mok et al., 2003, Dumont et al., 2008, Sekelja et al., 2010, Lovatt et al., 2015, Røen et al., 2018). By contrast, several studies reported that FCs lacked information provision (Shan et al., 2018,

Seal et al., 2015, Arber et al., 2013, Johnston et al., 2012, Harding et al., 2012, Duggleby et al., 2011, Maddalena et al., 2010, Stajduhar et al., 2008, Hudson, 2004, BrobÄCk and BerterÖ, 2003, Grbich et al., 2001, Aranda and Peerson, 2001, Rose, 1999). Aranda and Peerson (2001) reported participants lacking information about support available to them. This lack of information induced FCs' sense of isolation, stress and fear in many studies (Shan et al., 2018, Totman et al., 2015, Harding et al., 2012, Johnston et al., 2012, Duggleby et al., 2011, Linderholm and Friedrichsen, 2010, Grbich et al., 2001, Rose, 1999).

"Information about financial and other forms of support was commonly identified by the participants as lacking, indicating the need for health professionals to provide structured information to carers looking after a dying person at home." (Aranda and Peerson, 2001)

Figure 8.6. Studies extracts

This highlights that FCs information provision varied among studies. However, the link between of EoLC trajectory and rapid decline and the need for proactive information provision would require more emphasis in research. This could illustrate the nature of urgency of this type of support during this period.

- Family carers wellbeing support

A second source of support for FCs identified through this review involved support that contributed to their own wellbeing. Although FCs across the studies claimed that their support needs were rarely considered separately to the patient's needs, their experience of being

supported appeared explicit or implied from the interpretation of reviewed studies (Hudson, 2004, Exley and Tyrer, 2005, Holmberg, 2006a, Arber et al., 2013, Totman et al., 2015, Lovatt et al., 2015, Klarare et al., 2017, Robinson et al., 2017, Oosterveld-Vlug et al., 2019, Spelten et al., 2019). Types of FCs wellbeing support in this review involved HCPs' follow up and contact, emotional support, and social support.

Several studies illustrated that HCPs regularly contacted FCs to ensure their understanding of situation and adaptation to caregiving (Andershed and Ternestedt, 1998, Rose, 1999, Wennman-Larsen and Tishelman, 2002, Stajduhar et al., 2008, Totman et al., 2015, Opsomer et al., 2019). Stajduhar et al. (2008) argued that this protected FCs from feeling lonely and enhanced their coping. This indicates that although follow up and contact could be mainly a patient related intervention, FCs perceived it was beneficial for their wellbeing in terms of enhanced coping and minimising their sense of loneliness.

"She [nurse] phones and says, "Well, how are the things?" I think it does help because you're not alone. You feel like there is somebody there if you need them. If you need the help, there is help there. I think that makes it quite a lot [of difference to my coping]. Yes it does" (Stajduhar et al, 2008).

Figure 8.7. studies extracts

Another form of FCs' support involved the provision of emotional care which was crucial for FCs' wellbeing (Harding et al., 2012). Emotional support was experienced implicitly in several studies through

HCPs' attitudes that included supportive communication with FCs e.g. attentive listening, encouragement and timely response to their needs (Andershed and Ternestedt, 1998, Rose, 1999, Mok et al., 2003, Holmberg, 2006a, Dumont et al., 2008, Stajduhar et al., 2008, Luijkx and Schols, 2009, Sekelja et al., 2010, Epiphaniou et al., 2012, Lovatt et al., 2015, Totman et al., 2015, Klarare et al., 2017, Shan et al., 2018, Spelten et al., 2019). However, one of the studies exploring bereaved cancer FCs' experience of palliative care during patient illness and after death found that very few FCs exclusively received emotional support apart from PwC (Sekelja et al., 2010); likewise, other FCs in Wennman-Larsen and Tishelman (2002) study never mentioned HCPs as a resource for emotional support.

"they give emotional support by discussing topics of importance to patients and their families; by making patients and family members feel understood, volunteers help them to prepare for new developments."(Luijk and Schols, 2009)

"Although carers appreciated the team's supportiveness only a small number of them mentioned the psychological support and counselling provided to them and to the patients."(Sekelja et al, 2010)

Figure 8.8. Studies extracts

This review found a limited number of studies discussed the notion of emotional support during bereavement. One study reported that FCs bereavement follow up was through HCPs' visits, calls or offering counselling sessions which was helpful for some FCs and did not make any difference for others (Sekelja et al., 2010), By contrast, Maddalena

et al. (2010) noted that FCs in their study reported limited bereavement follow up due difficult access as a result of rural residency and transportation difficulty.

"In helping the carer with bereavement and coping after the patient's death half of the participants said that palliative care was helpful by phoning, providing counselling and showing a concern for the whole family. Dissimilarly, others felt that palliative care was unable to help afterwards and that the care that was given while the patient was alive was sufficient." (Sekelja et al., 2010)

"Participants also noted a lack of follow-up care available for caregivers, specifically bereavement care, following the death of loved ones. This was notable in all cases, but more so in the rural case study because of transportation issues and lack of service." (Maddalena et al , 2010)

Figure 8.9. Studies extracts

This suggests that experiences and preferences regarding bereavement emotional support were varied, since there was no consensus of its provision among different studies contexts and FCs differed in their preferences for it.

Social support was another form of FCs' support identified through some studies that linked to FCs' wellbeing. For instance, Arber et al. (2013) explored the caregiving experiences of FCs of persons with a primary malignant brain tumour. They found that social support was provided through attending hospice meetings that offered FCs an opportunity for socialization and sharing emotions with others in the same situation. Similarly, FCs in Sekelja et al. (2010) found that social

contact with HCPs gave them a space for social conversations they liked. Overall, opportunities for socialization were significant in relieving FCs' sense of isolation while caring for PwC at home (Harding et al., 2012, BrobÄCk and BerterÖ, 2003). By contrast, another study highlighted that FCs reported social isolation due to being confined to home due caring for PwC (BrobÄCk and BerterÖ, 2003). Other FCs in Harding et al. (2012) exploration of cancer caregiving support needs and challenges reported the need to be aware of caregiving support groups that could offer emotional support and time for socialization. This suggests that opportunities for socialization might be important for FCs' emotional wellbeing.

"Other forms of community support identified were the carers Meeting at the local hospice. The group was described as 'a licence to moan' a way of carers getting things off their chest." (Arber et al, 2013)

"Caregivers also identified a wish to be informed about available existing caregiver support groups. "Things like perhaps groups or counselling sessions" (Ca 10) "I did not know there was an association for caregivers which is a place of relief, for socialising…" (Ca 4)." (Harding et al , 2012)

Figure 8.10. Studies extracts

Respite care was another form of social support for FCs that gave them a chance to perform their household duties, engage in leisure activities or have adequate sleep and rest (Grbich et al., 2001, Exley and Tyrer, 2005, Luijkx and Schols, 2009, Arber et al., 2013, Lovatt et al., 2015). Some respite care concerns were noted such as difficulty in getting night respite and uncomfortably asking for household duties help

from respite care providers since, this was intertwined with standard patient care (Grbich et al., 2001). Moreover, confidence and trust in HCPs was a determinant for accepting home respite care (Lovatt et al., 2015). For instance, in the Arber et al. (2013) study some FCs were reluctant to accept this support and leave PwC with the assigned HCPs due to their limited confidence in their skills. Likewise, this added burden to other FCs (Robinson et al., 2017), since they felt they needed to supervise HCPs on duty to ensure that PwC needs were addressed. This highlights that respite care appeared beneficial for FCs wellbeing but, it could add to their strain in some instances.

"Nurses lessened the burden on carers by providing much needed respite care – giving carers the opportunity to sleep, or to leave the house for a short time." (Exley and Tyrer , 2005)

"It was also important for the HCAs to gain the trust of family carers as this allowed the family carers to perform normal, everyday tasks within the home, safe in the knowledge that while the HCA was present to oversee the clinical care". (Lovatt et al , 2015)

Figure 8.11. Studies extracts

Social support also appeared in the provision of complementary therapy sessions to FCs. Arber et al. (2013) noted that some FCs were offered an opportunity for complementary therapy e.g., massage when they accompanied PwC during their consultation. This was valued by those FCs as a social opportunity for relaxation.

"In this centre the carer and the patient have access to complementary therapies such as massage and the carer describes how this helps him with tension in his shoulders. Therefore, in this centre both the person with the brain tumour and the carer has a convivial social setting to relax and enjoy themselves". (Arber et al, 2013)

Figure 8.12. Studies extracts

In summary, two main sources of support were highlighted by this review that contributed to FCs' wellbeing either indirectly through patient care support or directly through an exclusive support for FCs. Certain types of support had less attention in the studies e.g., emotional, and social support which left unclear assumptions about whether they were not offered, or FCs had certain concerns for the way that support was offered. This would suggest the need for more in-depth investigation regarding support experiences and preferences in a general perspective rather than focusing on specific services.

3.4.3.b. Influencers of support experiences and care satisfaction

The support sources presented in the previous section were delivered through a professional relationship between the caring dyad and the HCPs. This relationship involved certain domains that made it either helpful and satisfactory or an unpleasant experience. The domains included the quality of the relationship between the FCs and HCPs, the responsiveness of the support services, and HCPs' specialized knowledge and skills.

- Quality of relationship

This domain discusses the varied nature and quality of FCs-HCPs relationship. Studies reported that FCs developed good relationship with HCPs which was based on mutual understanding, commitment and empathetic attitudes (BrobÄCk and BerterÖ, 2003, Epiphaniou et al., 2012, Arber et al., 2013, Lovatt et al., 2015, Totman et al., 2015, Klarare et al., 2017, Spelten et al., 2019). This enhanced connectedness and distribution of roles between FCs and HCPs (BrobÄCk and BerterÖ, 2003, Holmberg, 2006a, Linderholm and Friedrichsen, 2010, Duggleby et al., 2011, Totman et al., 2015). For instance, Exley and Tyrer (2005) indicated that in some FCs-HCPs interactions, professional and work boundaries were minimised through HCPs offering extra support hours than usual which was interpreted as HCPs displaying personal commitment. Other studies reported that HCPs shared their personal contact information with FCs (Oosterveld-Vlug et al., 2019, Røen et al., 2018, Klarare et al., 2017, Lovatt et al., 2015, Holmberg, 2006a, Exley and Tyrer, 2005).

"Indeed, a number of accounts would seem to suggest that some of the nurses were working outside their normal hours – a practice which was viewed by carers to show immense personal commitment." (Exley and Tyrer , 2005)

"Some GPs were even willing to increase their availability further still for the cancer patient and their relatives by giving their private telephone number. Having a good (pre-existing) bond with the GP possibly influenced such additional service."(Oosterveld-Vlug et al., 2019)

Figure 8.13. Studies extracts

However, in several studies it was reported that PwC was the main focus in these relationships which made FCs feel an outsiders (Wennman-Larsen and Tishelman, 2002, BrobÄCk and BerterÖ, 2003, Hudson, 2004, Milberg and Strang, 2004, Linderholm and Friedrichsen, 2010, Duggleby et al., 2011, Harding et al., 2012, Johnston et al., 2012, Ward-Griffin et al., 2012, Arber et al., 2013, McCaughan et al., 2019, Miranda do Vale et al., 2019, Oosterveld-Vlug et al., 2019). Therefore, some FCs developed the perception of the primacy of PwC needs and they made their own needs secondary and less in priority (BrobÄCk and BerterÖ, 2003, Hudson, 2004).

"But you know they came for him but were not here for me. They came for NN … and administered his medicine and took care of him. But when they were here at home felt left out. Then I was not part of it anymore (interview 6; ex-wife to a man diagnosed with prostate cancer". (Linderholm , and Friedrichen 2010)

". . . no, there is nobody who has been talking to me, asking me how I am doing, . . . if anybody asks about something I only say that everything is OK, you cannot say anything else .. The informal carers are often reluctant to disclose their needs to the professional carer because they do not think it is acceptable to do so. They do not want to put their needs for care before those of the patient." (Broback and Bertero , 2003)

Figure 8.14. Studies extracts

Family carers involvement in the care process was highlighted by some studies (Holmberg, 2006b, Ward-Griffin et al., 2012, Lovatt et al., 2015). For instance, Lovatt et al. (2015) noted that the HCPs supported FCs in care delivery through providing guidance and feedback about the

care delivered while respecting their views on the process of care provision.

"HCAs (healthcare assistants) were careful not to exclude family carers from caring for the patient, but instead provided them with the appropriate knowledge to allow them to care and reassured them that they were doing the right thing. " (Lovatt., et al, 2015)

Figure 8.15. Studies extracts

By contrast, in other studies HCPs expressed their encouragement of FCs' involvement, however, this did not happen in reality which made them felt insufficient and isolated (BrobÄCk and BerterÖ, 2003, Brazil et al., 2010, Ward-Griffin et al., 2012, Harding et al., 2012, McCaughan et al., 2019).

"I think it would be nice to be involved and be aware of what's going on (with spouse's care) . . . I guess I could have made myself available (when nurses visit) and I would have liked to see what was going on, but I didn't think that was what they wanted .." (Ward-Griffin., 2012)

"The next of kin often express this feeling of being an outsider: they are quite lonely as carer and they experience that nobody has concerns about them. Nobody asks them about their opinion and they feel insulted because they are the people who know their loved one best. Altogether, this makes them feel insufficient.. . ." (Broback and Bertero , 2003)

Figure 8.16. Studies extracts

Several studies noted that good communication was another determinant of quality of relationships between FCs and HCPs. This

appeared through FCs' reports of HCPs' respectful attitude, and empathetic and encouraging communication (Andershed and Ternestedt, 1998, Strang and Koop, 2003, Holmberg, 2006a, Holmberg, 2006b, Dumont et al., 2008, Luijkx and Schols, 2009, Linderholm and Friedrichsen, 2010, Sekelja et al., 2010, Epiphaniou et al., 2012, Arber et al., 2013, Lee et al., 2014, Lovatt et al., 2015, Totman et al., 2015, Klarare et al., 2017, Røen et al., 2018, Oosterveld-Vlug et al., 2019, Spelten et al., 2019).

"Her empathy, you know, her support, her understanding, was exceptionally one of the best ever I have come across. You know, and I feel that, you know when I see her, I'll always remember my mother." (P13) (Totman et al., 2015)

Figure 8.17. Studies extracts

Similarly, other studies noted that regular informing and feedback to FCs' enquiries increased the communication success (Røen et al., 2018, Totman et al., 2015, Epiphaniou et al., 2012, Linderholm and Friedrichsen, 2010, Holmberg, 2006b). In a study about communication in palliative care, Holmberg (2006b) indicated that communication and information facilitated the engagement comfortably in emotionally sensitive conversations about death and dying. Furthermore, HCPs communication and informing contributed to the FCs sense of security (Andershed and Ternestedt, 1998).

“Her realization of the son's dying was acknowledged, and thus, could be talked about, before her son had accepted the seriousness of his illness. She had the possibility to openly ask questions on what was almost forbidden to think about in her mind, much less talk about: her son's dying moment.” (Holmberg.,2006b)

“I was afraid she would suffocate, and that would be a horrid death. The doctor did not hear any secretions when he listened to her, and said that things were going to go the way they should. "She has no pain. That you can be sure of," he said, "and she's going to die soon." ... The doctor stayed a while and talked with us. We said that now we knew, and that we felt secure.... So he went home, but he said, "If you need anything call me right away, and I'll come right away." And this was a great reassurance.”(Andershed.,1998)

Figure 8.18. Studies extracts

By contrast, communication, and relationship breakdown was noted as a problem in several studies (Oosterveld-Vlug et al., 2019, Robinson et al., 2017, Arber et al., 2013, Strang and Koop, 2003). This was experienced if HCPs did not keep their promises especially for PwC’s admission when provision of acute supportive services were needed (Linderholm and Friedrichsen, 2010, Rose, 1999). Consequently, FCs felt emotionally distressed due to broken promises of support accessibility (Rose, 1999, Linderholm and Friedrichsen, 2010, Arber et al., 2013, Totman et al., 2015).

"Professional caregivers told us that she could stay at home as long as she wanted, and when she did not want to stay at home anymore, she would be admitted to the hospital ward… we trusted them and felt secure with this promise…..But then on the last day, when the doctor made her stay at home, I was frustrated and very frightened, did not know what was going to happen that night….. (Interview 13; man living with a woman diagnosed with uterine cancer)." (Linderholm, and Friedrichen 2010)

Figure 8.19. Studies extracts

Furthermore, Brazil et al. (2010) noted that communication breakdown was experienced when HCPs ignored FCs views in the care process and decision making. This echoed other studies where FCs' felt that only PwC's voices were legitimised and HCPs preferred that PwC being the point of contact rather than FCs (Oosterveld-Vlug et al., 2019, McCaughan et al., 2019, Shan et al., 2018, Arber et al., 2013, Richards et al., 2011).

"Poor communication between the family caregiver and the formal care providers was a noted problem, where caregivers reported a lack of sensitivity with respect to communication, lack of involvement in treatment decisions. The other nurse, um, came but she didn't have the compassion and had difficulty lifting him. But anyway it ended up that I had asked her to call me at night if he turned for the worse and she didn't do that the last night. She called just, I did see him just before he died and he smiled. She said she would call me at 3:00 a.m. and this was 4:30 a.m., so you know, I didn't hear, she had an hour and half to call me so. (CG 11) (Brazil et al, 2010)

"Although some experienced being pushed back as their concerns were not always taken seriously. For example, a daughter who recognized from her mother's facial expressions that she was in pain, felt she was not being taken seriously as the GP initially believed that the daughter only wanted to increase the morphine dose. Furthermore, in some cases the GP only acknowledged the patient as their contact person and only wanted to discuss medical information with the patient." (Oosterveld et al, 2019)

Figure 8.20. Studies extracts

However, insensitive, inappropriate and argumentative conversations that lacked respect for FCs were also reported in some studies (Strang and Koop, 2003, Hudson, 2004, Exley and Tyrer, 2005, Brazil et al., 2010, Duggleby et al., 2011, Arber et al., 2013, Totman et al., 2015).

'There was just one that was a bit off hand with me because I said about doing the syringe at night. I said "Can't the Marie Curie…?" "No. She is not allowed to..." She said "You can fill it and you can give it to him..." She was really nasty with me so I did complain about that and got an apology. I said well "look I am not a nurse; I have never used a syringe in my life'" (Carer 9).(Excely and Tyrer, 2005)

Figure 8.21. Studies extracts

Robinson et al. (2017) explored the experiences of bereaved FCs who were able to achieve home death for their family members with advanced cancer. The authors reported that some FCs were upset from HCPs judgemental assumptions about patient care. Whilst other FCs criticized HCPs for their upsetting and insensitive communication that negatively impact the FCs-HCPs relationship (Opsomer et al., 2019, Totman et al., 2015).

"Even when the palliative care nurse said to me, "I think it is time for you to have help,^ I objected. That was in the last week of (name)'s life. I said, "No, I have looked after him all along. I am going to continue to look after him.^ So, when she hit me with this, I was almost a bit resentful." (Robinson etal., 2017)

"And then the palliative homecare team that regularly called and wanted to come by. But, for myself, I decreased those two. We haven't actually built such a good relationship with the palliative team. Every time they came, they had bad news, and those people are focused on that, right." (*Opsomer et al., 2019)*

Figure 8.22. studies extracts

This review highlighted that FCs-HCPs quality of relationships varied depending on some aspects such as empathetic attitude and communication and FCs consideration and involvement in care which impacted the FCs' overall support experiences.

- Support services' response

This review discussed three aspects of support response that involved services' availability and proactivity, support adequacy, and support coordination. Proactive services' response and availability were valued aspects of FCs' support experiences in the reviewed studies that

offered them a peace of mind and control over the caregiving situation (Spelten et al., 2019, Richards et al., 2011). Services' availability appeared through FCs' contact with HCPs whenever needed (Opsomer et al., 2019, Richards et al., 2011, Sekelja et al., 2010, Linderholm and Friedrichsen, 2010). In such situations, HCPs encouraged FCs to contact them anytime they needed and making themselves available for support (Brazil et al., 2010, Sekelja et al., 2010). Similarly, Spelten et al. (2019) explored the experience of families and nurses with rural palliative care, they noted that FCs acknowledged the value of indefinite services' availability that facilitated caring at home for PwC.

"The husband received great support from the staff at HBHC and felt that he could contact them at any time. They came to the house on very short notice when necessary, even at night. He told about a number of conversations the family had with the doctor and nurse, without any feeling of their being pressed for time" (Andershed and Ternestedt, 1998)

"Family felt that the 24/7 availability of the nurses enabled their loved one to stay at home where they would otherwise have had to be referred to a hospital." (Spelten et al., 2019)

Figure 8.23. Studies extracts

However, several studies reported unsatisfactory experiences of support response. For instance, Some FCs found support in excess than their needs and time-consuming for them (BrobÄCk and BerterÖ, 2003). Whilst, other studies reported that unresponsive services and support inadequacy were significant problems (Grbich et al., 2001, BrobÄCk and BerterÖ, 2003, Strang and Koop, 2003, Exley and Tyrer, 2005, Brazil et al., 2010, Duggleby et al., 2011, Arber et al., 2013, Totman et al., 2015,

Shan et al., 2018, McCaughan et al., 2019, Miranda do Vale et al., 2019).This unsatisfactory support responsiveness was attributed to restrictions on support hours (Brazil et al., 2010, Exley and Tyrer, 2005) and the limited night professional support (McCaughan et al., 2019).

"The limitations in the availability of home support services manifested itself in a variety of ways, including the reported need for but lack of availability of 24-hour nursing care. The restrictions on the hours that we would get a month when you're dealing with somebody that has cancer of the brain and you know you're dealing with behavioural and mobility problems ...as well as the availability of physician home visits." (Brazil et al., 2010)

"they could promise day care, but they couldn't promise night care … (Relative /R10)" (McCaughan, 2019)

Figure 8.24. studies extracts

Service coordination and organization were other attributes of support response mentioned in several studies (Grbich et al., 2001, Lovatt et al., 2015, Klarare et al., 2017, Robinson et al., 2017, McCaughan et al., 2019, Spelten et al., 2019). For instance, coordinated services response appeared in HCPs' arrangements for medication provision, medical transportation and healthcare referral that was perceived as a safety net for FCs' while dealing with services (Totman et al., 2015, Holmberg, 2006a). Service coordination also appeared in HCPs' collaboration that was facilitated if services were delivered by the same HCPs that enhanced care continuity (Shan et al., 2018, Klarare et al., 2017).

"The nurses had prepared the pharmacy prior to my visit there. It was arranged for me to pick up all the things at the back entrance of the pharmacy, where I could bring my car. And for sure it was needed. The big boxes containing nutrition and infusion for a week were heavy. I did not have to explain anything. The nurses had prepared it all"(Holmberg, 2006 A)

"Caregivers described the value of being seen by the same professional providing care at home from the initial evaluation to a home death. This was usually the case for physicians, but not for nurses or personal support workers. When it did occur, it was greatly appreciated."(Shan et al., 2018)

"Another common thread running through the 37 care episodes in this theme is participants' descriptions of how both the collaboration between HCPs and the HCPs' approach provide the basis for experiences of continuity of care. This is described both as an experience of a continuous caring relationship, where HCPs know the participants and are familiar with their whole situation". (Klarare etal., 2017)

Figure 8.25. Studies extracts

On the other hand, incoordination and disorganisation of services appeared in various situations that triggered FCs upset (McCaughan et al., 2019, Oosterveld-Vlug et al., 2019, Shan et al., 2018, Robinson et al., 2017, Totman et al., 2015, Richards et al., 2011, Brazil et al., 2010, BrobÄCk and BerterÖ, 2003, Strang and Koop, 2003, Grbich et al., 2001). For instance, provision of services by multiple varied HCPs resulted in unexpected and uncoordinated visits and compromised care continuity, consistency and quality (Grbich et al., 2001, BrobÄCk and BerterÖ, 2003, Hudson, 2004, Stajduhar et al., 2008, Brazil et al., 2010, Arber et al., 2013, Shan et al., 2018).

"Home care services were structured in a way that did not always allow consistent care by the same personal support worker or nurse, or consistency in the quality of care".(Shan etal.,2018)

"Another problematic area they identified was the less than adequate coordination and scheduling of health services coming into the home. For example, one said; I found it very confusing because I never knew it wasn't at that time that this one came on this and that one came on that day. We never knew who was coming in and some were better with mom and some weren't". (Strang and Koop., 2003)

Figure 8.26. Studies extracts

Other issues of service incoordination were the poor HCPs' communication and collaboration that were reported in several studies (Strang and Koop, 2003, Hudson, 2004, Brazil et al., 2010, Richards et al., 2011). In some occasions, this resulted in the lack of consensus about treatment options which led to errors, delays and FCs' confusion about who was in the charge of patient care (Strang and Koop, 2003, Hudson, 2004, Brazil et al., 2010, Richards et al., 2011, Oosterveld-Vlug et al., 2019).

"However, if multiple disciplines from primary and secondary care were involved in the care for a patient, a proper transfer of information was not always guaranteed. Some interviewees felt that GPs and specialist physicians worked separately and hardly communicated with each other, which could lead to errors and miscommunication. To avoid this, patient and relatives took a more active role themselves. We learned to take control, otherwise you miss out on things. You see, he [the patient] has to deal with a nutritional team, with the oncologist in city A, the radiologist in city B, community nursing and the GP. Those are five channels. Well, that doesn't align well. Because the GP should receive information, but the radiologist sends it to us and to the oncologist but not to my GP. And he [the GP] has no contact with the community nurses, because they are from another city, you understand? So if you don't take good care of those things, and if they don't arrange it, then that injection you should be getting monthly doesn't happen, neither do medicines nor the blood sample that needs to be taken and analysed."(Oosterveld et al, 2019)

Figure 8.27. Studies extracts

This made FCs struggle in navigating the health system alone and in taking the responsibility for transferring information between services; following equipment liaison and delivery, otherwise miscommunication, mistakes and service delays could occur (Oosterveld-Vlug et al., 2019, Totman et al., 2015, Richards et al., 2011, Strang and Koop, 2003). This suggests that besides, in-home caregiving duties e.g., symptom management, personal care, FCs would engage in other coordinating and outdoor caregiving tasks e.g., getting and looking for a specific service that would increase their distress level and burden.

- HCPs' specialized knowledge and skills

Healthcare professionals' specialized knowledge and skills was the third domain of influencers of support experiences. Some studies attributed FCs' services' satisfaction to the competence of the staff and their profound experiences (Oosterveld-Vlug et al., 2019, Nielsen et al., 2013, Exley and Tyrer, 2005) . For instance, in a Canadian study, Nielsen

et al. (2013) examined the meanings of home condition negotiations of care for first generation Chinese immigrants with advanced cancer receiving palliative home care. They reported FCs' appreciation of HCPs' palliative care competence, expertise, educational preparation, and knowledge. This would suggest that if HCPs' provided competent care for PwC and their clinical judgement were accurate, this contributed to FCs' enhanced manageability and confidence in the care process (Robinson et al., 2017, Milberg and Strang, 2004).

"Palliative home care providers were seen as having expertise on dying at home. Their educational training, work with dying patients, and knowledge of the palliative care system was valued by care recipients and family caregivers, who had less experience with the system and death at home." (Nielsen et al, 2013)

"Participants reported that initiation of palliative care services enabled caregiving. Four important things came with formal palliative care: system recognition of them as caregivers, ***access to a highly qualified team****, better coordination of care, and the availability of a program of resources. System recognition involved attention to the FCG, acknowledgment of the critical work of caregiving, and concern for their needs as caregivers.* ***Skilled nurses assisted with assessing, identifying, and meeting needs****." (Robinson et al, 2017)*

Figure 8.28. Studies extracts

Other studies highlighted the significance of HCPs' interpersonal caring and empathetic skills besides medical proficiency (Oosterveld-Vlug et al., 2019, Røen et al., 2018, Lovatt et al., 2015, Sekelja et al., 2010, Exley and Tyrer, 2005).

"Carers described the palliative care team using terms such as "comfortable, easy, calm, nice, caring, sympathetic, understanding, pleasant, approachable and kind". Carers found them "indispensable" and felt that they "could not have done without them." (Sekelja et al , 2010)

"They are very respectful, and I also feel that they always check everything. My partner always wants to talk about books and politics and they all participate in that. But still, when things occur, they always check him to make sure he doesn't have pressure sores and things like that, without even specifically mentioning it. So they do check sensibly. I have confidence in that." (Oosterveld-Vlug et al., 2019)

Figure 8.29. Studies extracts

However, three studies criticized the HCPs' competency level that contributed to FCs' dissatisfaction with their support experiences (Arber et al., 2013, Richards et al., 2011, Strang and Koop, 2003). For instance, some FCs criticized out-of-hours staff for being general in scope and lacking the specialist knowledge and expertise (Richards et al., 2011). Similarly, Strang and Koop (2003) added that if HCPs were incompetent, this inflicted safety risks for PwC and added further burden on FCs who tried to correct care errors that would happen.

"Two people remarked that out-of-hours general practitioners (GPs) do not usually have the necessary expertise. Mr EM remarked, '(y) of course they can only generally, I guess, be GPs or like, not specialists in a particular field', whereas Mrs HT said, 'Very nice doctors but, they, I don't know, they're general." (Richards et al, 2011)

"There were stronger themes relating to how formal support systems added strain to the caregivers' abilities to manage. They spoke of how service provider incompetence added to. Rather than reduced, their responsibilities of caregiving. For example; Then when the PCA (person care aide) came to bathe home who hadn't given anyone a bath with oxygen. She had the oxygen hooked up with his pants. She did! And so I ended up having to go in and sort of fix everything anyway." (Strang and Koop, 2003)

Figure 8.30. Studies extracts

In summary, three aspects of formal support delivery were identified through this review that influenced FCs' support experiences. These aspects included relationships quality, the support services response and HCPs' specialized knowledge and skills. Although the cited studies offered a valuable insight into FCs' support experience, their link to the distinct characteristics of EoLC and associated experiences e.g., changing disease trajectory and prognostic uncertainty was limited. This would suggest the need for further research to highlight these links more clearly.

3.4.3.c. Impacts of support experiences

In the previous two sections about support experiences, the sources of support and influencers of support experiences were described. These sections highlighted the medium in which support was delivered were closely linked to another major theme describing the overall impacts of support experiences. These impacts originated through FCs' dealing with

formal support that included emotional wellbeing, coping with caregiving demands and the trust in healthcare services and professionals.

- Emotional wellbeing

Emotional wellbeing was presented in various studies in the form of emotional security or relief which was perceived as an emotional construct that evolved through positive support experiences (Andershed and Ternestedt, 1998, Rose, 1999, Aranda and Peerson, 2001, Wennman-Larsen and Tishelman, 2002, Mok et al., 2003, Strang and Koop, 2003, Milberg and Strang, 2004, Holmberg, 2006a, Dumont et al., 2008, Stajduhar et al., 2008, Sekelja et al., 2010, Richards et al., 2011, Totman et al., 2015, Klarare et al., 2017, Robinson et al., 2017, Shan et al., 2018, Røen et al., 2018, Oosterveld-Vlug et al., 2019, Spelten et al., 2019, Opsomer et al., 2019). This review identified several factors that contributed to this sense of emotional security. For instance, provision of support sources that facilitated coping with caregiving at home were a precursor for emotional relief. In their study, Klarare et al. (2017) mentioned that HCPs home adaptation to suit care provision contributed to this sense of emotional security. The authors attributed the sense of emotional security associated with home environment adaptation to its role in facilitating caregiving coping at home environment. This gave FCs the emotional reassurance that they could deal with caregiving smoothly and safely. Similarly, information provision and caregiving skills training were also associated with this sense of emotional security (Sekelja et al., 2010, Stajduhar et al., 2008).

Another important aspect of security was the experiences of the HCPs adjusting the practical aspects of care to accommodate patients' and families' situations. In the care episodes, the work of PTs and OTs in modifying the home environment to make home care possible was especially prominent and mentioned by all participants. Many described practical things—such as getting a hospital bed delivered and set up, or adjusting bathroom facilities, and organizing schedules according to the participant's wishes. As one family member stated.They have been here and checked what's needed. We have a stair lift and a walker and a toilet seat extension, .. . we've received incredible help, haven't had to fight for anything. It has come along very smoothly. (P2) (Klarare et al., 2017)

"Many carers reported feeling a lot more reassured having access to palliative care nurses to answer questions and provide information as well as teach caring skills such as wound dressing." (Sekelja et al., 2010)

Figure 8.31. Studies extracts

Unconditional availability of support was another common contributor to emotional security in various studies (Opsomer et al., 2019, Shan et al., 2018, Røen et al., 2018, Klarare et al., 2017, Dumont et al., 2008). This was maximised through dealing with familiar HCPs that reflected continuity and coordination of care (Stajduhar et al., 2008, Holmberg, 2006a, Totman et al., 2015, Robinson et al., 2017, Klarare et al., 2017, Shan et al., 2018)

"The carers were confident that palliative care would be available when needed, both in specialist and community care; this made them feel safe. It's extremely good to have the Home Care. That's a safe reference point, because that's every day the whole year, you know. […] When you need it, they're there (6, 225–229)."(Røen et al ., 2018) "Being known by the HCPs and experiencing continuity in the care received was a relief for participants" (Klarare et al , 2017)

Figure 8.32. studies extracts

Other studies, argued that emotional relief was triggered through supportive communication processes with HCPs that were achieved through care related conversations, and time for questions and answers which contributed to an environment of trust where FCs felt acknowledged (Oosterveld-Vlug et al., 2019, Holmberg, 2006a, Holmberg, 2006b, Rose, 1999). This suggested that HCPs represented a comfort zone where FCs felt supported and their concerns were handled properly (Spelten et al., 2019, Totman et al., 2015, Sekelja et al., 2010, Stajduhar et al., 2008, Holmberg, 2006a).

"It was a great relief to her to communicate with the palliative home care team. She felt acknowledged by the nurses and the physician." (Holmberg, 2006b)

Figure 8.33. Studies extracts

In another point of view, other authors (Mok et al., 2003, Rose, 1999) argued that emotional relief was experienced if FCs perceived that HCPs were working for the PwC's welfare and that they would not suffer while being cared for at home. This developed a sense of emotional relief and security that enhanced FCs' confidence in the care process, relieved their anxiety and helped them to prepare for their grief and bereavement (Mok et al., 2003, Dumont et al., 2008, Sekelja et al., 2010, Lovatt et al., 2015, Shan et al., 2018, Spelten et al., 2019).

"Carers often expressed a sense of relief if someone could reassure them that the patient would not suffer and that they would not be left alone to cope: Anyway, the doctor said he wouldn't suffer…And he said to me, `If you're worried about him, or if you see him deteriorating a great deal, you must ring'. Oh, he was lovely; I just can't get over him." (Rose.,2001)

"Indeed, clinicians offered security, a listening ear, information, and support essential to moving through the stages of the patient's end of life, which had positive repercussions on adjustment to bereavement." (Dumont et al., 2008)

Figure 8.34. Studies extracts

However, other studies reported several negative emotional experiences such as emotional insecurity, social isolation, exclusion, helplessness and insufficiency that were experienced by FCs due to unfavourable support service experiences (1999, Grbich et al., 2001, BrobÄCk and BerterÖ, 2003, Milberg and Strang, 2004, Linderholm and Friedrichsen, 2010, Duggleby et al., 2011, Harding et al., 2012, Johnston et al., 2012, Ward-Griffin et al., 2012, Seal et al., 2015, Totman et al., 2015, Miranda do Vale et al., 2019). Although Ward-Griffin et al. (2012) contended that some FCs considered these negative emotions as a normal part of the caring stress process, others referred these negative emotions to the inability of HCPs to provide or guide them to available support (Duggleby et al., 2011, Arber et al., 2013).

Linderholm and Friedrichsen (2010) explored the FCs' caring experiences and support during the patient's final illness and after their death. They argued that emotional insecurity was developed when FCs experienced a lack of HCPs information and guidance which made them feel helpless and ignored. Similarly, feelings of social isolation, exclusion, disappointment, helplessness, despair and insufficiency were

experienced if support was limited; communication with the health system was insufficient and FC's needs were not considered or they were not involved in the care process (Miranda do Vale et al., 2019, Seal et al., 2015, Totman et al., 2015, Ward-Griffin et al., 2012, Johnston et al., 2012, Harding et al., 2012, Linderholm and Friedrichsen, 2010, Milberg and Strang, 2004, BrobÄCk and BerterÖ, 2003).

"There were situations of unclear information about what the professionals expected from them, and this contributed to a feeling of insecurity and the family caregivers felt isolated and vulnerable." (Linderholm and Friedrichsen, 2010)

"Feeling unsupported gave rise to feelings of isolation. Most participants mentioned at least one occasion when they felt let down by professionals, and several described the desperation they felt when alone at a time of need". (Totman et al., 2015)

"As one spousal caregiver explained, the primary focus on the client contributed to feelings of isolation, marginalizing the family caregiver from the situation. . .. But usually I got the impression that they came to attend to [husband's] needs and that was it, so . . . I would just get out of the way."(Ward-Griffin et al., 2012)

Figure 8.35. Studies extracts

Similarly, these negative emotions and distress were heightened if FCs felt embattled and were chasing the services for any support that might be needed (Oosterveld-Vlug et al., 2019, Totman et al., 2015). Other studies added that distress and loneliness were experienced when FCs perceived the HCPs assertion to keep PwC at home, in spite of the FCs' inability to cope with PwC's deteriorations and limitations of support (Linderholm and Friedrichsen, 2010, Milberg and Strang, 2004).

"For the five participants who had particularly difficult experiences, there was a sense of embattlement, of having to fight for their family member's needs to be met: I constantly had argumentative discussions, which is not pleasant, I'm not happy to do that, but I have no other choice, to be able to have these very hard conversations with those individuals concerned. (P14)." (Totman et al., 2015)

"Interactions with HBHC had for a few of the informal carers contributed to a feeling of isolation. These informal carers had felt pressured by the staff, who openly or symbolically expressed home as the preferred place of care, while the informal carer was very isolated with his or her fear of situations of acute deterioration." (Milberg and Strang., 2004)

Figure 8.36. Studies extracts

Emotional security was perceived as a key aspect of emotional wellbeing that could be achieved through reliable formal support services. However, studies were limited in the discourse of potential long-term emotional constructs that could be experienced such as the sense of reward and achievement which could be facilitated by formal support experiences.

- Coping with caregiving demands

Several studies reported that effective formal support enabled FCs to cope with the caregiving demands which was achieved through several aspects of formal support (Mok et al., 2003, Holmberg, 2006b, Stajduhar et al., 2008, Dumont et al., 2008, Epiphaniou et al., 2012, Lee et al., 2014, Røen et al., 2018). For instance, some studies argued that caregiving preparedness through HCPs' information and guidance enhanced FCs' coping (Lovatt et al., 2015, Luijkx and Schols, 2009, Stajduhar et al., 2008, Aranda and Peerson, 2001). Other studies added that HCPs' encouragement enabled smooth and effective caregiving at

home (Mok et al., 2003, Dumont et al., 2008, Holmberg, 2006b, Stajduhar et al., 2008, Epiphaniou et al., 2012, Lee et al., 2014, Røen et al., 2018).

"Information on how to care for the patient (eg, bathing, toileting, feeding, and managing pain) and on the health and social services that were available to them was most relevant and useful in helping caregivers to cope." (Stajduhar et al., 2008)

Figure 8.37. Studies extracts

Lee et al. (2014) argued that HCPs' encouragement while involving FCs in care increased their confidence to cope with caregiving at home. This gave FCs' a sense of shared responsibility with HCPs and facilitated caregiving coping (Milberg and Strang, 2004). Similarly, other caregiving coping determinants involved acknowledging FCs' contributions in PwC's care, while considering their needs for support and helping them in care coordination and navigation (Robinson et al., 2017, Totman et al., 2015). Thereby, FCs were able to care for PwC at home and maintain a dignified home death through dedicated formal support (Luijkx and Schols, 2009, Chapple et al., 2011, Robinson et al., 2017, Spelten et al., 2019).

"Most (70%) caregivers in this study regarded health professionals as important people they could rely on for support, thus boosting their self-confidence in continuously caring for the patients at home. "I appreciated the support from home care nurses … their encouragement made me feel self-confident to care for my mom at home. (son)". (Lee et al, 2013)

"Some of the relatives we interviewed explained that with the help of palliative care nurses, such as Marie Curie nurses, a dignified home death had been achieved." (Chapple et al, 2011)

Figure 8.38. studies extracts

It seemed that HCPs depended on FCs to support PwC at home and required FCs to have the knowledge and the ability to seek help at the right time (Linderholm and Friedrichsen, 2010). However, if FCs managed these responsibilities alone and their roles were taken for granted without acknowledgement for their contributions, their coping was diminished (Milberg and Strang, 2004, Linderholm and Friedrichsen, 2010, Duggleby et al., 2011, Totman et al., 2015, Oosterveld-Vlug et al., 2019).

"The period following a patient's discharge from hospital could be particularly challenging, as relatives found themselves suddenly alone with their caring responsibilities:… like that first night we came home from the hospital was just – we felt really, I was really sad, because suddenly when we left the hospital I realised we were on our own. (P9)". (Totman et al., 2015)

"Isolation could also concern being left outside, not regarded as a contributing resource in relation to the patient. For example, when the informal carer was not recognised by the health care staff as an important support for the patient in a burdening situation, this hampered a feeling of manageability." (Milberg and Strang., 2004)

Figure 8.39. Studies extracts

Limited FCs' preparation (Arber et al., 2013, Harding et al., 2012, Aranda and Peerson, 2001), and support inadequacy were significant precursors for impaired coping (McCaughan et al., 2019). FCs would struggle while dealing with caregiving tasks that they were not prepared for (Harding et al., 2012). Support inadequacy increased FCs burden that made some of them purchasing private nursing support which added financial burden and ultimately was less beneficial due to its time limitation (Shan et al., 2018, Brazil et al., 2010, Grbich et al., 2001). While those who were unable to afford for private support, their endurance diminished and EoL admission was their only solution for getting relief and resolve their caregiving struggle (Shan et al., 2018).

"Preparation was important in managing the significant practicalities that their role involved, such as funeral issues: "If he dies I know the procedure…but I just don't know how to get it there and how it works when someone dies in this country" (Ca 8)". (Harding et al., 2012)

*"Adequate nursing support (e.g., district, Macmillan and Marie Curie nurses) was considered essential for relatives to provide care at home, and 'gaps', particularly overnight, were described as detrimental to relatives' capacity to cope: [home care] was never feasible unless we had much more support". (*McCaughan*, 2019)*

"Those who could not afford private help often felt they needed to provide more support than they were comfortable with: "I couldn't do it all. CCAC needs more resources." (C314C), "… it basically throws all that heavy nursing on family members" (C-269C). For some, this lack of support resulted in admissions at the end of life." (Shan et al., 2018)

Figure 8.40. Studies extracts

This suggests reliable formal support was a crucial factor that either enhanced or hindered FCs' coping, however, this ultimately focused on their role continuity without clear attention to latent meanings and experiences attached to the enabled coping such as sense of achievement.

- Trust in healthcare services and HCPs

Trust in the healthcare system and HCPs was interpreted as another impact of support experiences that was identified in this review. It was apparent that if FCs were well supported by HCPs and their needs were addressed along with PwC's needs, this embraced a sense of trust in HCPs (Spelten et al., 2019). Meanwhile, the trust in the healthcare system was reflected in the willingness of some FCs in Richards et al. (2011) study to reuse the support services (out of hours services), since their experience was pleasant.

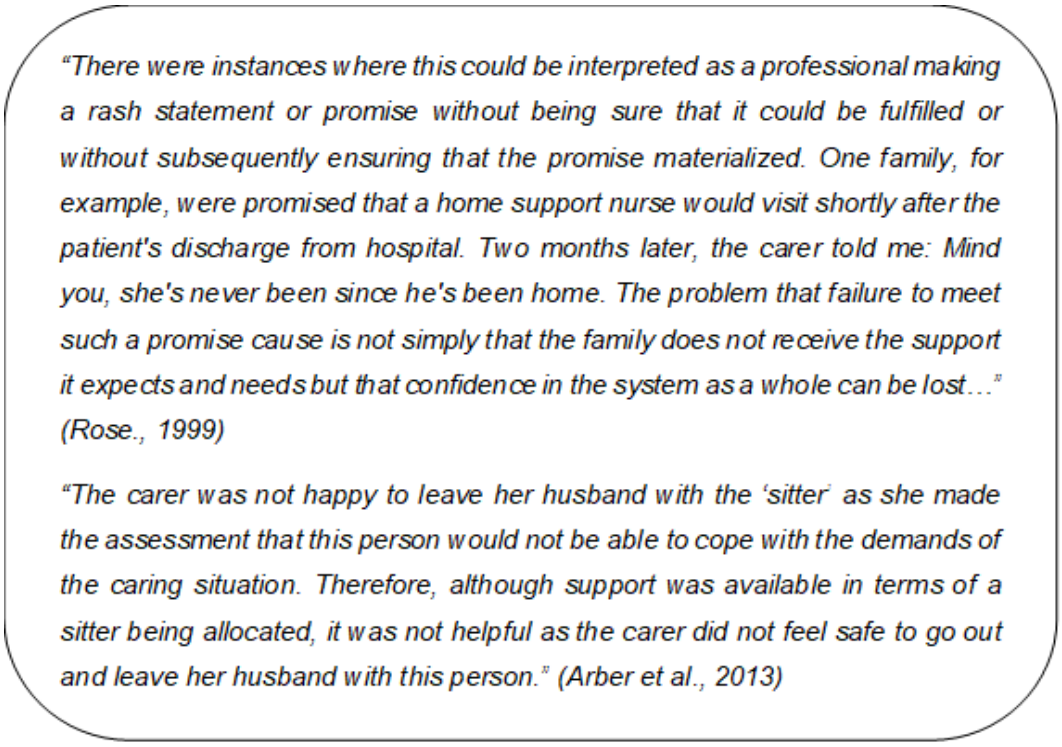
"The staff members were closely attuned to the wishes of each individual patient and their families. All families felt the nurses were there equally for the patient and the families. There was a high level of trust in the nurses even if the service was required for a short time. Oh, ten out of ten… they were… you could not help but actually bond with them." (Spelten et al. (2019)

"I think what we'll say was that our whole experience was a good one and that erm, if we needed to use it then we were very confident about it". (Richards et al.,2011)

Figure 8.41. Studies extracts

However, trust in the healthcare system and HCPs was threatened on some occasions where communication breakdown was experienced, or HCPs incompetence was evident. For instance, Rose

(1999) noted that some FCs in the study reported that broken promises about support availability had challenged their confidence in the healthcare system. Similarly, Arber et al. (2013) mentioned that some FCs in their study criticized the social care staff's competency which triggered their mistrust in the visiting HCPs that led to losing the benefits of available support.



"There were instances where this could be interpreted as a professional making a rash statement or promise without being sure that it could be fulfilled or without subsequently ensuring that the promise materialized. One family, for example, were promised that a home support nurse would visit shortly after the patient's discharge from hospital. Two months later, the carer told me: Mind you, she's never been since he's been home. The problem that failure to meet such a promise cause is not simply that the family does not receive the support it expects and needs but that confidence in the system as a whole can be lost…" (Rose., 1999)

"The carer was not happy to leave her husband with the 'sitter' as she made the assessment that this person would not be able to cope with the demands of the caring situation. Therefore, although support was available in terms of a sitter being allocated, it was not helpful as the carer did not feel safe to go out and leave her husband with this person." (Arber et al., 2013)

Figure 8.42. studies extracts

Although trust in the healthcare system and HCPs was interpreted from a limited number of studies, it was apparent that it was an element of support experience that could be developed through FCs-HCPs interactions; however, this would need further exploration in research. In summary, this section highlighted the potential role of positive support experiences in developing favourable impacts such as emotional wellbeing, enhanced caregiving coping and trust in the healthcare system and HCPs.

3.5. Discussion and critique of reviewed literature

3.5.1. Discussion of findings

This review cited a number of studies that captured the FCs' experiences of formal support. However, these studies either explored certain types of support services e.g., out of hours (Richards et al., 2011) or were a part of a trial program (Spelten et al., 2019) which could result in a limited view of FCs' support experiences. Many studies were limited in terms of the higher level of interpretation and scope of support experiences; satisfaction or dissatisfaction aspects of support were highlighted with limited inferences regarding the evidence of how and why this happened and what were the related consequences of satisfaction or dissatisfaction. However, it could be argued that was not the main aim and objectives of the primary studies to highlight these specific experiences. This suggests the need for further research to develop a comprehensive interface of cancer FCs' support experiences at EoL.

In the previous discourses in Sections 2.3,2.5., it was noted that FCs' play a significant role in providing physical and psychosocial care for PwC at EoL and achieving a dignified death experience at home if they wished (Brazil et al., 2010, Perpiñá-Galvañ et al., 2019). However, this could negatively impact their physical and psychosocial wellbeing (Rowland et al., 2017). Therefore support for FC's could be an important factor that facilitates caregiving coping and enhances FCs' wellbeing (Beth, 2018, Gilbert et al., 2010); this should be a priority for healthcare services planning (Larsson et al., 2016).

This review explored the experiences of FCs of PwC receiving home-based EoLC services. However, it was apparent that their experiences of support varied significantly; they were positive on some occasions and negative in others. This suggested that satisfaction with EoLC support depends on the personal experiences of FCs and the contextual environment of services that influenced the types of support available, its accessibility and how it was delivered. In a quantitative review exploring home-based family caregiving at EoL, Stajduhar et al. (2010) noted that predictors for satisfaction in formal services were the configuration of support services regarding individualisation, adequacy and type of services provided; specialist or generic services. However, the authors asserted that care perceptions were a predictor for support satisfaction that involves FCs' understanding and expectations of care and support. Therefore, formal support services evaluation and research needs to be conducted regularly to ensure support services recommendations are congruent with the changing needs and contexts of the society.

This review discussed the FCs' support experiences in three main themes that involved the sources of support that were available to FCs, influencers of support experiences and the impacts of support experiences. Support was classified broadly into patient care support that was related to services aimed solely or have the relation to patient care e.g., symptom management; and FCs' wellbeing support that involved types of services that facilitate FC's coping and enhance their wellbeing e.g emotional support. However, patient-focused support was the dominant form of support offered or mentioned in the studies which might

suggest that little consideration was given to the FCs' position as care recipients. For instance, some types of support appeared fundamental to FCs e.g., symptom management support, while other support that involved household help and respite care was less mentioned by the studies. Similarly, emotional support was found to be limited or was provided informally and implicitly through FCs' relationships with HCPs.

In a similar view, Morris et al. (2015) conducted a narrative review about the perspectives of FCs providing support to a person dying at home. The authors argued that support deficits were existed for both patients and FCs. However, FCs' unmet support needs were heightened and more specifically, emotional support. It was not clear from the reviewed studies whether FCs did not pay attention to these support sources; it was not a priority for them or has not been offered, which could be explored in future research. In their qualitative review, Funk et al. (2010) highlighted that FCs ambivalence about their needs would be a barrier to support access, since FCs would be afraid of bothering HCPs with their unmet needs. Whilst, in earlier arguments of Nolan and Grant (1989), the authors alluded to the implicit perception of the healthcare system about the position of FCs as a resource for the continuation of caregiving process at home; this could have a role in the focus on patient care support interventions.

In an editorial, Hudson (2013) argued that bereavement support should be widely offered to FCs and allocated funding, since FCs are likely to struggle during this difficult period. The existing EoLC policies and frameworks advise about the importance of access to support and

planning throughout the caregiving trajectory and during bereavement (Hansford and Meehan, 2007, Department of Health, 2008). However, this review noted that FCs in some studies (Sekelja et al., 2010, Maddalena et al., 2010) were left feeling vulnerable during bereavement and the bereavement support experiences of the caregiving journey received little attention in the majority of the studies. This suggests the need for integrated evidence of the overall support experiences throughout and beyond the caregiving journey.

This review identified three factors that influenced FCs' support experiences that included the quality of relationship with HCPs, support services response and HCPs specialized knowledge and skills. Enhanced relationship with HCPs were developed through mutual understanding, commitment, informed communication, and empathetic attitudes towards the caring dyads. Similarly, several authors highlighted that compassionate and trustful relationship and communication between HCPs and FCs formed a fundamental aspect of favourable support experiences at home (Rogers et al., 2000, Beach et al., 2005, Shiozaki et al., 2005, National Audit Office, 2008, Funk et al., 2009, Funk et al., 2010). This could trigger FCs' emotional security, optimism, and relieve their sense of distress and anxiety while providing care (Martín et al., 2016, Funk et al., 2010). It was apparent that support availability, proactive response and coordination, HCPs' collaboration and competence received a significant attention in the reviewed studies that was contributed to enhanced caregiving coping and FCs' support satisfaction (Martín et al., 2016, Funk et al., 2010). Although this review

provided multiple evidence for satisfactory support experiences regarding availability and response, there was evidence of stressful experiences due to limited support availability and poor coordination. This suggests the need for further exploration of support experiences and suggesting practical recommendations for managing these challenges in the changing context of EoLC.

In the present review the connection between FCs' support experiences and the potential caregiving consequences and impacts were evident. In other words, if FCs had positive experiences with the support services and HCPs (i.e. quality relationship with HCPs, support availability and coordination, HCPs' competence and collaboration), FCs emotional wellbeing could be enhanced through the developed sense of security (Martín et al., 2016). This could facilitate their coping with caregiving responsibilities (Funk et al., 2010) and strengthen their confidence in the healthcare system and HCPs. However, limited evidence was noted regarding the notion of trust in the healthcare system and HCPs which could warrant further exploration in research. Similarly, it was apparent that reviewed studies remained focussed on the immediate impacts of support experiences pertaining to the role of FCs (e.g., enhanced FCs' coping), and the emotional impacts (e.g., emotional security) that linked to the caregiving continuation at home. However, there was limited attention to other potential impacts e.g., rewarding caregiving experiences, that could contribute to a favourable appraisal of FCs' role actualisation; the potential role of support services in facilitating or hindering these rewarding experiences needs to be explored.

In summary, FCs' experiences of EoLC support at home were mixed and varied across healthcare models and studies' contexts. Services' improvement is needed to reflect FCs' needs and expectations for support and facilitates cancer EoL caregiving at home while preserving FCs' quality of life and wellbeing. The present study will address the knowledge gaps that were identified in this review. For instance, the need for higher-level interpretation of FCs experiences using a theory building methodology to facilitate designing supportive interventions for FCs. Moreover, this study would help exploring the less reported notions of FCs' support experiences such as emotional support and the facilitation of rewarding caregiving experiences at EoL which will be discussed in Section 3.5.3.

3.5.2. Strengths and limitations

The current review provided a global view of FCs' support experiences over different periods of time in different contexts, since it was not limited by the study country or publication date. However, limiting the search to English language studies due to inaccessibility for translation services could be a limitation. Although the search was conducted in four electronic data bases; this was preceded by a scoping search to determine the breadth of literature and the selected data bases were more relevant to the review question. Reference lists screening increased the ability to identify other studies that could have been missed; however, some studies might have been overlooked. This review constituted part of PhD project; thus, studies eligibility screening and data extraction was conducted by a single researcher which could be a source

of bias. However, regular debriefing and discussion with the supervisory team provided a critical instance to the process and the development of the review themes. Lastly, this review was limited to primary research in peer reviewed journals, since the principal purpose of this review was to identify the robust studies to date which will help in informing and shaping the present study and bridge the knowledge gaps in the literature. This could provide recent practical recommendations to enhance EoLC and FCs' support practice.

3.5.3. Research implications and justification for the present study

Research exploring FCs' support is required to understand the complex nature of supporting PwC at EoL at home and the changing contextual factors that interplay and shape FCs' support perceptions (Grande et al., 2009, Funk et al., 2010). This could facilitate the understanding of enabling and constraining factors in getting support from formal services.

Notably, this review highlighted that much research has been done to explore cancer FCs' support at EoL to offer policy and practice recommendations. However, FCs' still experience several challenges with the health and social care support services and their experiences are not considered when planning EoLC services (Houses of Parliament, 2018, Gonella et al., 2019). This suggests the need for further research to bridge the gap in knowledge regarding FCs' support at EoL.

Most of the cited studies had a limited perspective of FCs' experiences of EoLC support that only formed a part of the main purpose of the

studies. Therefore, there was limited evidence on certain aspects FCs' support e.g., emotional support and bereavement care.

Although caregiving experiences appear homogenous, the trajectory of caregiving changes with the specific dying trajectory of terminal diseases (Penrod et al., 2012). Most of reviewed studies did not provide a precise definition of EoL period or they tended to use **"Palliative phase"** as a defining term. However, the first refers to the last twelve months of life that is associated with distinct caregiving experiences. Considering this ill-defined nature of EoL period in many studies, approaching the present study with a specific definition for EoL is advisable (Grande et al., 2009). Similarly, future research should explore the dynamics of the caregiving process at EoL with more focus on formal support interactions to capture the differing FCs' support needs and experiences across EoL trajectory (Penrod et al., 2012, Wilkinson and Lynn, 2005).This could help developing trajectory specific strategies and allow for proper judgement regarding the findings' transferability (Guerriere et al., 2016, DuBenske et al., 2008). Furthermore, defining FCs lacked consensus among studies and many of them did not provide a clear definition for FCs which is needed to be considered in the future research to develop contextual evidence for FCs' support. This review noted that studies were more reliant on recruiting bereaved FCs as research participants. However, there is a need for comprehensive examination of FCs' experiences throughout caregiving trajectory that necessitates considering the views of current, former and bereaved FCs (Grande et al., 2009).

Holmberg (2006a) argued that support is considered a process of social interaction. However, this review highlighted that studies tended to focus on descriptive aspects of satisfaction or dissatisfaction of the services with limited inferences regarding the process of how and why this happened and what are the related consequences of satisfaction or dissatisfaction. Therefore, FCs' support experiences need exploration in a way that highlights the different aspects of support interactions and its connection to the caregiving process and potential short term and long-term consequences.

This review highlighted that studies tended to focus on immediate support experiences and caregiving impacts and outcomes e.g., enhanced coping, and the role of formal support services in achievement of these outcomes. However, this reflects the limited view of caregiving and formal support experiences that could contribute to improved long-term outcomes such as meaning making and the sense of reward. Furthermore, this review reported limited evidence regarding some of the impacts of support experiences such as trust in the healthcare system and HCPs. This indicates the need for further research to develop evidence regarding these potential long-term impacts and outcomes.

Ultimately, qualitative exploration should be considered for future research to highlight the impact of context on FCs' experiences and their constructed meanings of formal support interactions and its possible implications on the caregiving journey (Gilbert et al., 2010). Likewise, the need for proper theoretical and conceptual models is evident in the literature to guide the development of theoretically driven interventions

for FCs at the EoL (Penrod et al., 2012, Grande et al., 2009, Nolan et al., 1995). However, this review noted that only four studies used a grounded theory design. This suggests further research is needed that adopts a theory building methodology to develop a theoretical interpretation of FCs' support experiences and offer support recommendations that are theoretically grounded on research data.

Based on these assumptions; aims, and objectives were developed to fill the identified knowledge gaps.

Aim of the study

To explore FCs' experiences and perceptions of using formal support services received while caring for PwC at EoL.

Objectives of the study

- Elicit FCs' experiences and views about formal support services received while caring for PwC at home during their last year of life.
- Explore situations where FCs needed more or less formal support.
- Analyse the factors that enable or constrain quality formal support experiences for FCs of PwC.
- Elicit FCs' perspectives on the extent to which formal support matched their expectations.
- Provide recommendations for health and social care professionals regarding appropriate EoL support for FCs of PwC.

For achieving these objectives, the following strategies and actions were adopted.

- Applying for a national ethics committee and seeking Health Research Authority (HRA) approval and Research and Development (R&D) approvals at the participating sites.
- Recruiting a purposive sample of FCs of PwC who received EoLC at home.
- Conducting qualitative interviews to explore FCs' experiences of formal support.
- Analysing interviews and identify core categories and develop a theory that explain FCs' lived experiences.
- Discussing the findings regarding existing literature and develop recommendations for policy, practice, education, and research.

3.6. Chapter summary

This chapter presented a narrative synthesis that explored the experiences of FCs of PwC regarding EoLC services. It provided a critical evaluation of the current research and identified research gaps for this PhD study. It discussed the study rationale with a statement of study aim and objectives. In the following chapter, the study methodological approach will be discussed.

CHPATER FOUR: METHODOLGY

4.1. Chapter introduction

In the narrative review chapter, it was clear that there is a need for a further study to fill the knowledge gaps reported in section 3.5.3. Thus, the present study was planned with an overall aim to explore FCs' experiences and perceptions of using formal support services received while caring for PwC at EoL. In this chapter, the methodological foundation of the present study will be discussed. The chapter starts with an overview of the qualitative research and the philosophical instances of this study. Qualitative approaches will be introduced with a particular focus on the chosen methodology **"Constructivist grounded theory" (CGT)**. Study procedures regarding participants' recruitment, data collection and analysis and ethical considerations will be presented. Lastly, this chapter concludes by a discussion of the study rigour and trustworthiness and a statement of reflexivity.

4.2. Choosing a research paradigm

The research approach is the researcher's wider plan of adopted procedures for undertaking a research activity (Myers, 2013, Creswell, 2018b). However, the research approach ultimately relies on two crucial aspects; the researcher's paradigm that illustrates the philosophical views regarding knowledge creation and reality; and the nature of the phenomenon under investigation. These two aspects primarily influence the researcher's decision regarding the research design and methods of inquiry, data collection and analysis (Creswell, 2018b).

The research paradigm reflects the views of the researcher about the nature of what constitutes a truth and world reality (Levers, 2013). The positivist research paradigm mostly depends on quantitative research methods and dominated in medical and social sciences' studies up to the mid of the twenty century (Broom and Willis, 2007).This paradigm depends on a realist ontology which claims that reality is an objective external construct that is independent of people's views and can only be discovered through senses (Ryan and Sfar-Gandoura, 2018, Chalmers, 2013, Ritchie and Lewis, 2003). This world view contends that human behaviors and experiences can be explored using objective measures (Chalmers, 2013). Mostly, the positivist paradigm depends on deduction as an epistemological approach that involves using an existing hypothesis or framework in the process of evidence testing (Ritchie and Lewis, 2003). However, it gives little attention to the contextual factors that could influence human experiences that are difficult to be controlled in a natural experiment (Chalmers, 2013).

The interpretive paradigm increasingly appeared in social sciences research in 1960s-1970s and primarily asserts the use of qualitative research (Broom and Willis, 2007). This paradigm is based on idealist ontology which contends that reality is socially constructed and can be described through human understanding and meanings ascribed to it (Ritchie and Lewis, 2003). This means that there are multiple subjective realities that are best explored through people's narratives about their experience of certain phenomenon. In the interpretive paradigm, there is more reliance on the inductive epistemological approaches to create

knowledge in which the data are first generated to define the studied phenomenon and structure theories and knowledge (Ritchie and Lewis, 2003). However, this paradigm is value laden where the researcher's behaviours, characteristics and relationship within the research context could influence the knowledge created (Antwi and Kasim, 2015, Ritchie and Lewis, 2003). Therefore, the researcher's reflective process and the acknowledgement of potential bias are significant in the interpretive research paradigm.

It was apparent from the study aim and objectives that the foundation of this study is exploring a human experience and perceptions of the caregiving process and the formal support experience in a health-related context. Authors have argued that the use of interpretive qualitative approach in health research helps in the understanding of human experience and FCs in particular where caring relationships and communication are essential (Robbins and Robbins, 1998, Holloway and Galvin, 2016). This can help develop individualised health services that meet the needs of people and make their experience better (Holloway and Galvin, 2016). Therefore, interpretive research approach and qualitative methods seemed appropriate for addressing the study aim and objectives.

4.3. Determining an interpretive qualitative approach

Qualitative research is a naturalistic inquiry that is interested in the description and interpretation of participants' meanings ascribed to their experience of certain phenomenon (Thomas, 2010, Yilmaz, 2013, Creswell, 2018b). Qualitative research involves a wide array of

approaches for exploring human experiences such as ethnography, phenomenology, and grounded theory (Holloway and Galvin, 2016, Kruth, 2015). It mostly depends on in-depth interview, observation, and document analysis for qualitative data collection with a special interest on the contextual nature of these data (Thomas, 2010, Saldana et al., 2011, Yilmaz, 2013).

The forementioned qualitative methodologies share a common interest in exploring an experience of certain phenomenon; however, they differ in their focus, lens, and methods of exploration (Kruth, 2015, Creswell, 2018a). In consideration of this study aim and objectives, ethnography and phenomenology were perceived less beneficial designs for the present study approach. For instance, the nature of participant observation, which is mostly advised in ethnographic studies, is subject to ethical criticism (Goulding, 2005); the emotional nature and complexity of EoL context in the present study and the participants' vulnerability could have caused ethical concerns. Although observation would facilitate exploration of FCs' behaviours while providing caregiving at home, this approach could be challenging in terms of examining FCs' perceptions regarding the support at EoL. Furthermore, ethnographic research requires an extensive amount of time for prolonged engagement which was difficult in the time limitation of a PhD study. Examining the present aim and objectives, shows that the focus of this study was not to explore the caregiving cultural aspects, behaviours and beliefs which are essential characteristics of ethnographic investigation (Creswell, 2018a). For these reasons, ethnography was perceived

unsuitable to explore the FCs' experiences about the support and EoLC services in this study.

The review of literature in this study and its aim and objectives reflected the need for moving beyond description and interpretations regarding caregiving and formal support to develop a theoretical understanding of EoLC in the family caregiving process. This study orientation required a methodology that facilitates explanation and deeper analysis of the dynamic social processes which could be evident in the FCs' experiences of support at EoL; this appeared difficult to be achieved using phenomenological approach where its focus is to provide an overall description of the essence of the experiences rather than explanation or offering a deeper analysis into the caregiving phenomenon (Kruth, 2015, Creswell, 2018a). Furthermore, the notion of "Bracketing" was found unhelpful for this study (Creswell, 2018a); the researcher's personal and professional assumptions could be useful in creating a common ground with FCs to enrich the discussion and explore the phenomenon more deeply. However, I acknowledged and accepted the possibility of challenging my own perceptions and presumptions.

Grounded theory is a methodological foundation for building theories and based on an inductive approach for developing theoretical explanation from empirical data (Alemu et al., 2017, Rieger, 2019). Grounded theory facilitates exploring how people experience and behave through everyday situations and explore the impact of social structures on people's behaviours (Starks and Brown Trinidad, 2007). It aims to move beyond the description to more abstract concepts that

define a process or behaviours in a theory that could provide explanatory models for practice and offers research implications (Strauss and Corbin, 1998, Creswell, 2018a).

By considering this critical discussion regarding the characteristics of different qualitative designs, grounded theory appeared as a suitable option for this study for the following reasons. Firstly, grounded theory could help in exploring the process of interactions which occurs between different individuals e.g., FCs, PwC, HCPs (Creswell, 2018b). In this study, it was important to explore these interactions, and their impacts on FCs' experiences. Moreover, in their review about EoLC at home, Funk et al. (2010) contended that experiences of home based EoL services and formal support satisfaction is underdeveloped and requires developing an abstract theoretical interpretation and not just merely a description which mirrors the narrative review's research implications. Therefore, grounded theory was perceived suitable approach to address the research gaps identified in the narrative review.

4.4. Selecting among grounded theory designs

Grounded theory was firstly introduced by Glaser and Strauss (1965) who explored dying in a hospital. They claimed to establish rigorous qualitative research through systematic data analysis for developing a theory that described a social process in the data (Glaser, 1967, Charmaz, 2014, Rieger, 2019). However, Charmaz (2000) described Glaser grounded theory as having an objectivist epistemology and realist ontology and it aims to discover unbiased new knowledge. In other words, the researcher enters the field with few thoughts to be open

for nuances of data; their role is a distant observer for the data emergence (Charmaz, 2014). Glaser advises against reviewing of literature prior to data collection and the research begins with no definite question (Charmaz, 2014, Rieger, 2019). Although the approach of Glaser appears more rigorous in the process of theory development, the notion of delaying the review of literature at the beginning of research is considered impractical and difficult to attain (Charmaz, 2006). Rieger (2019) argued that Glaser grounded theory would lead to a superficial understanding of the studied phenomenon due to its reliance on overt meanings that are captured by the researcher. This implies that Glaser's approach gives primacy to the researcher's interpretations over the participants' voices which would contradict the interpretive paradigm (Charmaz, 2014, Rieger, 2019). Later, Strauss and Corbin (1990) developed their grounded theory approach to provide a more prescriptive and systematic way of doing this kind of qualitative inquiry (Strauss and Corbin, 1998, Charmaz, 2014). They acknowledged that researchers' experiences and exposure to literature could enhance their theoretical sensitivity and interpretive analysis (Rieger, 2019). Therefore, they positioned that the literature review is useful to inform the research question and develop a base for making data comparisons. However, this approach was criticized by forcing the data into the categories due to their specific technical procedures for data analysis and using of coding paradigms that would limit the researcher's interaction with data and its emergence (Rieger, 2019, Charmaz, 2014).

A third approach of grounded theory was developed through the work of Charmaz; a student of Glaser and Strauss who became a leading scholar of Constructivist Grounded Theory (CGT) (Mills et al., 2006). In CGT, knowledge is socially constructed and co-created through a social interaction between the researcher and study participants (Mills et al., 2006, Charmaz, 2014, Levers, 2013). This contends that multiple realities exist and the focus of research inquiry is to explore the reality as perceived by the participants through their communication and behaviours (Mills et al., 2006, Rieger, 2019).

Charmaz (2014) argued that reality evolves in the mind of the viewer (i.e., researcher) and its meaning is relative to the relationship between the viewer and the viewed (i.e., research participants). Therefore, the researcher is considered a co-creator of the research process and the outcome knowledge (Charmaz, 2014, Ghezeljeh and Emami, 2009, Charmaz, 2000). This implies that interpretation of the studied phenomenon is created through a collaboration between the researcher and research participants (Charmaz, 2014).

Rieger (2019) indicated that the selection of the specific grounded theory approach should be based on study purpose, philosophical approach and practicalities regarding the available time and scientific support.

Constructivist grounded theory acknowledges the possibility of multiple explanations of the phenomenon for the purpose of developing theoretical understanding of a positioned social process rather than

identifying variables or explanatory theory as in classical grounded theory (Rieger, 2019, Charmaz, 2014). This supports the purpose of this study to explore FCs' experiences of EoLC services; this would help developing a theoretical interpretation of the process of caregiving and formal support at EoL while considering the different realities, situations, and contexts of FCs.

Several authors advise choosing a research methodology that is congruent with the philosophical assumptions (Crotty, 1998, Rieger, 2019). CGT emphasizes the relativist ontology and subjective epistemology which is congruent with the study's philosophical instance (Mills et al., 2006, Charmaz, 2014, Rieger, 2019). CGT also provides clear procedures for executing this methodological approach and simultaneously offers flexibility for creative theory development that supports the notion of theory emergence rather them using a preconceived framework (Rieger, 2019, Charmaz, 2000). Considering these earlier arguments, CGT seemed suitable for the present study perspective, aim and objectives. CGT has general features that are shared with other grounded theory approaches, however, it has distinct characteristics regarding some issues, such as the treatment of the literature, coding and generating the theory (Rieger, 2019, Alemu et al., 2017, Mills et al., 2006). In the following (Table 3.) the main features of CGT are presented:

Table 3. Features of constructivist grounded theory

Features	Explanation
Social process investigation	CGT researchers aim to understand meanings of people's behaviours and their change overtime in social context for developing a theory that describes the social processes involved in the phenomenon and were identified from the data (Maz, 2013, Rieger, 2019).
Literature review prior data collection	Researchers' exposure to the theoretical and conceptual background in their field makes it impractical to assume that researcher would ignore preconceptions about the phenomenon prior data collection (Charmaz, 2014). Thus, review of literature help to develop a general overview of possible dimensions of the phenomenon under investigation (Strauss and Corbin, 1998).
Logical induction and data emergence	Inductive approach in knowledge creation involves developing theoretical explanation that is grounded in the data collected and not enforcing any preconceived theoretical framework (Charmaz, 2014, Rieger, 2019).
Data collection intertwined with analysis	Grounded theory investigation is an iterative process in which data analysis is conducted at the same time while data is being collected to guide further data collection activities (Maz, 2013).
Using constant comparison	Constant comparative approach is a distinct feature of grounded theory in which data is compared to data in a single interview and between different interviews to determine the properties of identified social process through identifying similarities and differences (Glaser, 1967, Maz, 2013, Charmaz, 2014, Rieger, 2019)
Writing memos	It involves documenting the analytical thoughts about emergence of codes and categories and the relationship between them to develop theoretical interpretation (Charmaz, 2014, Rieger, 2019).
Theoretical sampling and theoretical saturation	Theoretical sampling involves collecting more data to suffice the developed categories and find out their comprehensive properties until no data incur further theoretical insights to define the developed theory which means the analysis reached to the theoretical saturation (Willig, 2008, Charmaz, 2014, Rieger, 2019).
Generating a theory grounded in the data	Grounded theory approach contends to develop an abstract theoretical explanation grounded on the data of the phenomenon experienced by research participants (Rieger, 2019). However, this theoretical explanation is only one substantive interpretation that pertaining to specific context and circumstances of the research process and the studied phenomenon (Charmaz, 2014).

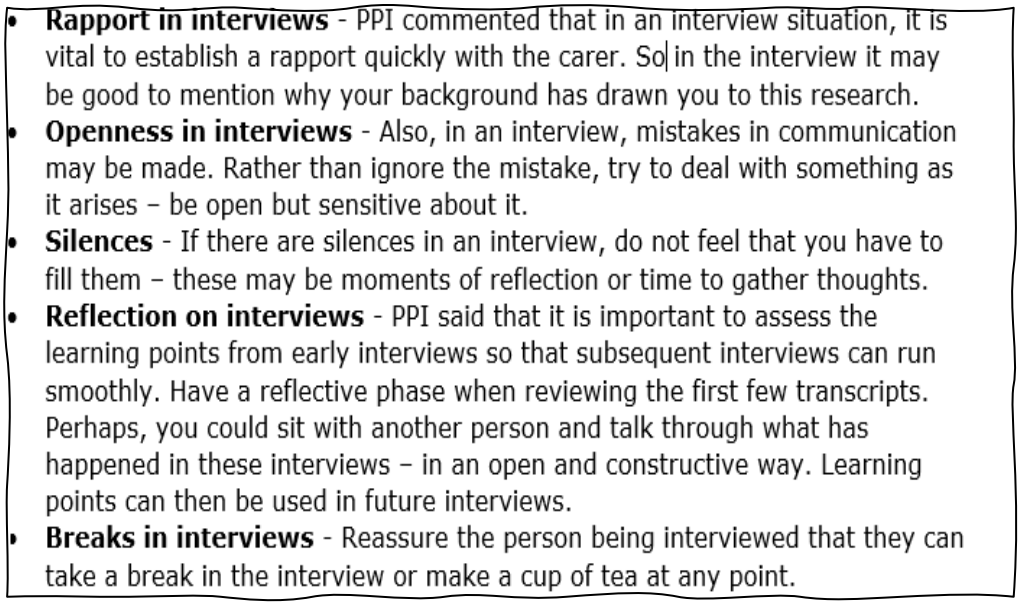
4.5. Research methods and procedures

Research methods involve decisions regarding how the research data will be collected, analysed, and interpreted (Creswell, 2018b). This section starts by a description of the study context which is followed by a discussion of sampling strategies and participants' recruitment process. Data collection methods will be discussed, and the application of CGT analysis will be explained. The ethical principles underpinning this study and ethical dilemmas encountered will be addressed. Lastly, the notion of study rigour and trustworthiness will be discussed with an overall reflexive statement of the study process.

4.5.1. Public and patient involvement

In the study planning phase, it was important to consider a Public and Patient Involvement (PPI) process; this is considered to help in shaping and influencing the direction of healthcare research (Gray-Burrows et al., 2018). In this study, the aim and objectives, participant recruitment procedures and participant documents (e.g., Participants Information Sheet (PIS), invitation letter, consent form and interview topic guide) were reviewed by a PPI group. It was The University of Nottingham Dementia, Frail Older People and Palliative Care Patient and Public Advisory Group Panel. A formal meeting was conducted prior applying for ethics with some of the group members who were FCs of PwC. The purpose of this step was to ensure that the study reflected the priority research needs of FCs and identify any potential concerns regarding the participation documents, and more specifically the proposed interview questions (Gray-Burrows et al., 2018). The PPI group

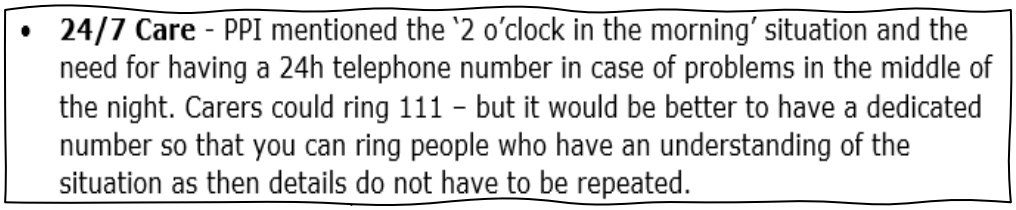
declared the importance of this study and the relevance of interview questions. They made some useful suggestions (Figure 9.1-3) regarding the interview conduct such as the importance of early rapport building, sensitivity while dealing with bereaved FCs and the significance of silences and breaks during the interview. They noted the importance of reflecting on early interviews to inform and enhance further interviews conduct.



- **Rapport in interviews** - PPI commented that in an interview situation, it is vital to establish a rapport quickly with the carer. So in the interview it may be good to mention why your background has drawn you to this research.
- **Openness in interviews** - Also, in an interview, mistakes in communication may be made. Rather than ignore the mistake, try to deal with something as it arises – be open but sensitive about it.
- **Silences** - If there are silences in an interview, do not feel that you have to fill them – these may be moments of reflection or time to gather thoughts.
- **Reflection on interviews** - PPI said that it is important to assess the learning points from early interviews so that subsequent interviews can run smoothly. Have a reflective phase when reviewing the first few transcripts. Perhaps, you could sit with another person and talk through what has happened in these interviews – in an open and constructive way. Learning points can then be used in future interviews.
- **Breaks in interviews** - Reassure the person being interviewed that they can take a break in the interview or make a cup of tea at any point.

Figure 9.1. PPI suggestions

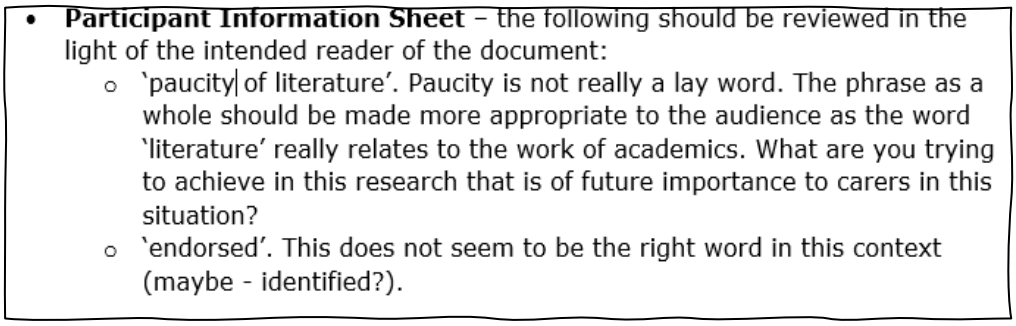
They also highlighted some important topics to be explored with the potential participants, such as the availability of 24/7 support and out of hours care.



- **24/7 Care** - PPI mentioned the '2 o'clock in the morning' situation and the need for having a 24h telephone number in case of problems in the middle of the night. Carers could ring 111 – but it would be better to have a dedicated number so that you can ring people who have an understanding of the situation as then details do not have to be repeated.

Figure 9.2. PPI suggestions

The PPI group suggested amending some terms in the PIS that seemed more technical and not suitable for lay persons.



- **Participant Information Sheet** – the following should be reviewed in the light of the intended reader of the document:
  - 'paucity of literature'. Paucity is not really a lay word. The phrase as a whole should be made more appropriate to the audience as the word 'literature' really relates to the work of academics. What are you trying to achieve in this research that is of future importance to carers in this situation?
  - 'endorsed'. This does not seem to be the right word in this context (maybe - identified?).

Figure 9.3. PPI suggestions

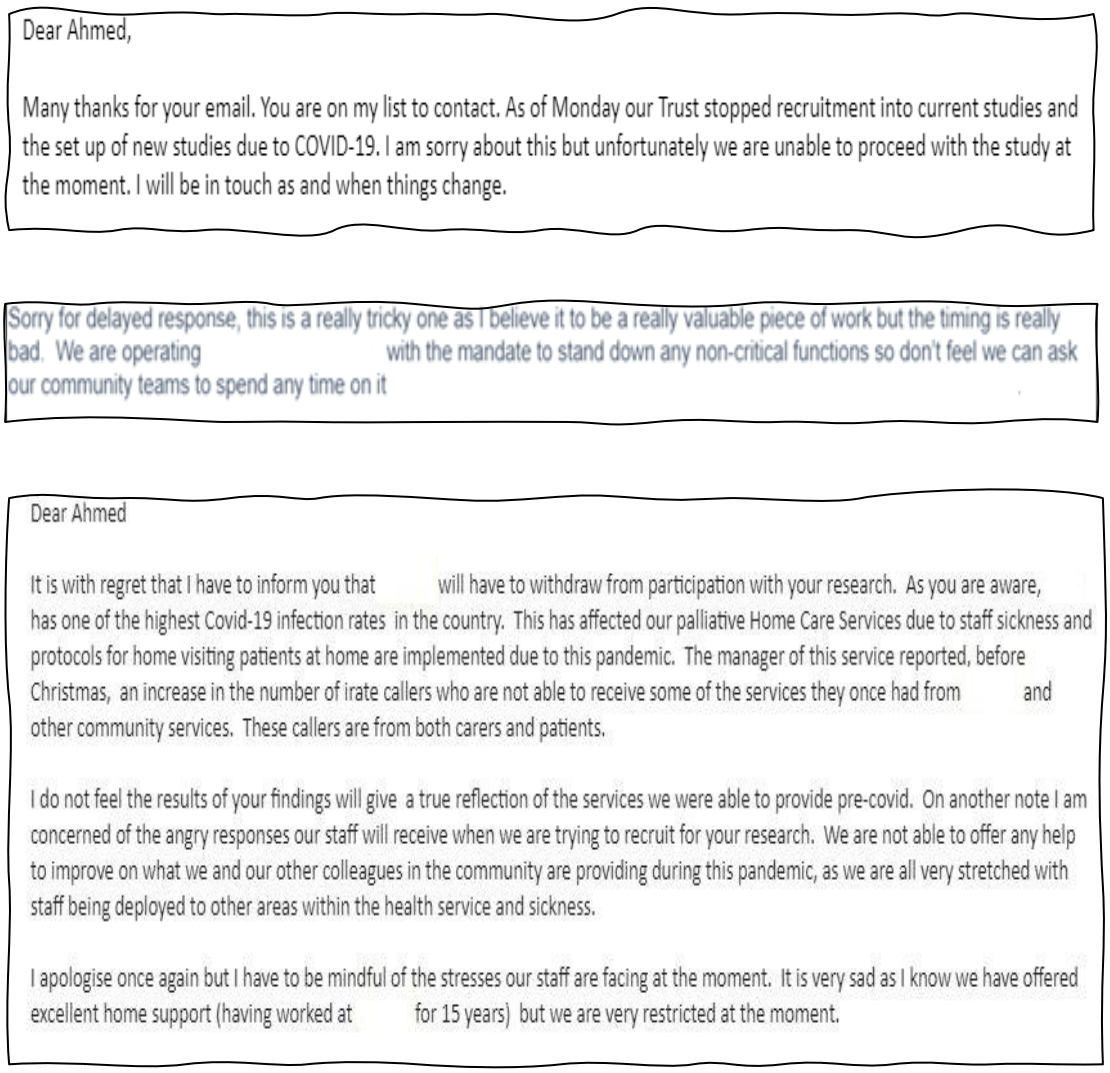
These suggestions were followed whenever possible to ensure the emotional safety of participants and achieving the scientific value of the study which helped in preparing for national ethics application and conducting the field work.

4.5.2. Study settings

Participants were recruited through four healthcare settings; a specialist palliative care unit affiliated to a teaching university hospital in the East midlands; two hospices in the East midlands; and another hospice in the Southeast of England. These settings provide a range of services for people with palliative care needs and their FCs, such as inpatient and outpatient services, counselling and bereavement services, complementary therapy, and day care therapy for social activities for patients and their FCs.

The selection of study settings is a determinant for feasible participants' recruitment and data collection activities (Horne, 2011). Therefore, some considerations were noted when selecting the study sites. Firstly, easy accessibility was important for potential study setup

visits and interviews. Secondly, I was keen to explore variations and differences in FCs' support experiences which could be impacted by variations in health and social care services' coverage and availability in different localities. Therefore, different settings were chosen to represent varied healthcare contexts e.g., palliative care units, community health services, hospices, and voluntary organisations for PwC support and FCs. This could facilitate exploration of the different FCs groups (e.g., current, bereaved, former FCs) with various contextual factors and inform the different dimensions of the potential theoretical interpretation. Although it was planned to include more diverse settings than those actually approached and recruited, the emergence of the COVID pandemic and national lock down in March 2020 led to a withdrawal of some research sites after their initial expression of interest. This was because of their inability to support the recruitment due to the pressures on the services during the pandemic (Figure 10.)



Dear Ahmed,

Many thanks for your email. You are on my list to contact. As of Monday our Trust stopped recruitment into current studies and the set up of new studies due to COVID-19. I am sorry about this but unfortunately we are unable to proceed with the study at the moment. I will be in touch as and when things change.

Sorry for delayed response, this is a really tricky one as I believe it to be a really valuable piece of work but the timing is really bad. We are operating with the mandate to stand down any non-critical functions so don't feel we can ask our community teams to spend any time on it

Dear Ahmed

It is with regret that I have to inform you that will have to withdraw from participation with your research. As you are aware, has one of the highest Covid-19 infection rates in the country. This has affected our palliative Home Care Services due to staff sickness and protocols for home visiting patients at home are implemented due to this pandemic. The manager of this service reported, before Christmas, an increase in the number of irate callers who are not able to receive some of the services they once had from and other community services. These callers are from both carers and patients.

I do not feel the results of your findings will give a true reflection of the services we were able to provide pre-covid. On another note I am concerned of the angry responses our staff will receive when we are trying to recruit for your research. We are not able to offer any help to improve on what we and our other colleagues in the community are providing during this pandemic, as we are all very stretched with staff being deployed to other areas within the health service and sickness.

I apologise once again but I have to be mindful of the stresses our staff are facing at the moment. It is very sad as I know we have offered excellent home support (having worked at for 15 years) but we are very restricted at the moment.

Figure 10. Communication with research settings excerpt

The enrolment of the study in the National Institute for Health Research (NIHR) portfolio facilitated study visibility to other NHS research settings across England. Furthermore, some participants were approached through one NHS trust intranet network in the East Midlands that were originally unable to support the study through their official healthcare setting as highlighted earlier.

Similarly, online recruitment was introduced that did not impose any limits on the population locality or particular settings that will be explored in detail in Section 4.5.4. This helped in the achievement of the study multi-site approach and recruitment of FCs in different contexts.

4.5.3. Sampling strategies

Sampling in qualitative research and grounded theory in particular aims for collecting sufficient data to develop theoretical properties of the core categories and identify the patterns and relationships among the theoretical concepts (Glaser, 1967, Strauss and Corbin, 1998). Authors suggest that defining a suitable sample size is crucial to obtain sufficient data for achieving theoretical saturation (Charmaz, 2006, Strauss and Corbin, 1998, Glaser, 1967). Theoretical saturation is a special feature of grounded theory that is achieved if data redundancy occurs, theoretical categories are well developed, and patterns and relationships between theoretical concepts are well established (Charmaz, 2006, Strauss and Corbin, 1998, Glaser, 1967). However, the ability to achieve theoretical saturation is determined by various factors, such as the research question, nature and sensitivity of the research topic, researcher experience and interviewer skills (Morse, 2000, Sobal, 2001). A range of 10 – 30 interviews is considered likely be sufficient to achieve data saturation in a grounded theory study (Creswell, 2018a, Thomson, 2011). However, achieving the required sample size is impacted by recruitment practicalities, such as research delivery staff, funding and available time for data collection activities (Robinson, 2014). Thus, adopting a flexible approach to sample size is advisable to conform with

time limitations (Robinson, 2014). This could be achieved through combining data analysis with data collection activities to determine if more interviews were needed to suffice the properties of the developed theory (Strauss and Corbin, 1998, Glaser, 1978).

In this study, a planned maximum target of 50 FCs of PwC was decided to ensure that saturation was achieved and counteract potential challenges such as participants' withdrawal or non-informative low-quality interviews.

Selection of a sampling strategy should align with the aim of the study and the philosophical underpinnings (Campbell et al., 2020). This study aimed to explore varied experiences and perceptions of FCs of PwC regarding formal support at the EoL. This suggests the need for specific participants who experienced EoLC services to have the credible knowledge that would inform the development of the theoretical interpretation of this experience. Given that the interpretive paradigm and CGT were adopted for this study, this proposes multiple realities and the importance of capturing experiences from people who lived through the studied phenomenon; a purposeful sampling strategy was determined an appropriate approach for this study (Charmaz, 2014, Thanh and Thanh, 2015, Campbell et al., 2020). Purposeful sampling is described as a method to identify specific research participants based on the purposeful benefits of their insights and information that could enhance understanding of the experienced phenomenon (Creswell, 2018a, Robinson, 2014). A purposeful sample of FCs of PwC was suggested to include participants who fulfilled the following criteria:

- Current or former primary FCs for PwC who were defined as those members of a family who fulfilled the role of main unpaid caregivers of a patient during the last year of life (Dumont et al., 2008) (then multiple main FCs for the same PwC was considered; details are given later in this section).
- Bereaved FCs were approached primarily within the time frame of 3 months up to 2 years of PwC's death. However, this was amended later where bereavement status was not restricted by a timeline. This was necessary to overcome the experienced challenges during participants' recruitment. By doing that, potential participants beyond this timeframe expressing willingness to participate (either due to them responding to online recruitment strategies or facing bereavement between the start of recruitment to the study and actual participation), were included in the study.
- Received formal support at home from health and social care services or voluntary organisations.
- Be 18 years or older.
- Speak English.

Grounded theory traditions assert the notion of theoretical sampling for achieving theoretical saturation of the developed categories (Glaser, 1978, Charmaz, 2014). Theoretical sampling is described as a method that involves concurrent data collection and analysis to provide direction for further data collection activities that could inform the developing theory (Glaser, 1978). Thereby, the sampling goals progressed from an

open wide perspective to sample the variations that represented the possible dimensions of the theoretical categories (Coyne, 1997, Glaser, 1978). Thus, after each interview the emerging issues and plausible conceptions were considered to be explored in further interviews. For instance, the first interview addressed the issue of the working-caring dilemma which indicated the necessity of continuing interviews to explore this issue further among working FCs. This led to the emergence of a sub-category regarding dealing with competing responsibilities which contributed to the chaotic caregiving experience, explored in detail in Chapter five. However, I continued to recruit working and non-working participants equally to elaborate on the other competing responsibilities with caregiving.

As mentioned earlier, the principal eligibility criteria indicated that primary unpaid FCs were the primary target of proposed sample. However, the identified ideas from the first interview about caregiving teamworking as a way of adapting to the caregiving chaos, triggered the interest of including multiple primary unpaid caregivers to explore this aspect further. This ultimately, created a sub-dimension of sharing caregiving as a coping strategy with caregiving chaos. Formal support experience was the main aim of the study therefore, it was explored in all interviews. However, the issues of services' coordination and communication started from the second interview which was investigated further in later interviews. This accounted for an important dimension of the second theoretical category **"Interacting with formal support "**. Similarly, the concept of quality time experience with PwC was raised

from the second interview. This has been explored further and echoed in other later interviews that constituted a part of the reward/guilt and regret experiences of the developed theory. Therefore, the theoretical sampling helped in developing the theoretical categories in this study and provided an opportunity to achieve theoretical saturation (Charmaz, 2014, Glaser, 1978).

However, theoretical saturation is needed to be treated as an aim rather than ultimate reality and the resultant theory is a provisional version that could be added to or modified (Glaser, 1967, Willig, 2008). This indicated that although, theoretical saturation was aimed, it is not an absolute guarantee to be achieved (Willig, 2008). For instance, in this study there was an intention to sample more current FCs which could have enriched the developed categories. However, the nature of EoL caregiving, uncertainties and time practicalities limited this opportunity. In this study, some current FCs withdrew after their initial approval due to deterioration of PwC. Whilst another FC experienced the death of PwC in between the period of invitation and interview. This highlights the uncertain nature and challenges of the sampling experience. By the end of data collection process, a total sample of 26 FCs of PwC were recruited into the study which achieved theoretical saturation.

4.5.4. Participants recruitment

Participants' recruitment in EoLC research is challenging due to the sensitive and emotional nature of this kind of research and the potential ethical issues that could arise during the study (Stiel et al., 2015). Therefore, a gatekeeping recruitment approach was perceived suitable

to ensure the recruitment of a sample of FCs who are able to contribute to the study while considering their safety and emotional wellbeing. However, online recruitment was used when the COVID pandemic started.

4.5.4.a Study set up and gatekeeper contact

Gatekeeping involves the actions of individuals that facilitate or constrain the accessibility to potential research participants (Kirchhoff and Kehl, 2007). Gatekeepers also have the responsibility to make sure that research participants are safe and not being exposed to any potential risks (McFadyen and Rankin, 2017). In this study, after obtaining regulatory approvals, an initial contact was made with research delivery staff at potential study sites (two specialist palliative care units at two different teaching university hospitals, two community health services, four hospices in the East Midlands) to introduce the study purpose and their potential role in the recruitment process. However, before starting study set up at the research sites the COVID pandemic emerged, and national lock down occurred in March 2020; a detailed study regimen is presented in the next section (Figure 12.). This led to pausing the study recruitment activities and withdrawal of some sites (one specialist palliative care unit, one community health service and two hospices in the East Midlands) due to staff shortage and redeployment. However, a regular follow up was kept with the existing research sites (a palliative care unit, a community health services setting and two hospices) regarding the study status update. This significant challenge required introducing some study amendments such as using online

recruitment and remote interviewing and consenting to adapt to the current context of the pandemic and overcome recruitment problems.

In September 2020, study setup was revisited again at the remaining sites (a specialist palliative care unit, a community health services setting and two hospices in East Midlands) and onsite recruitment commenced in November 2020. The adoption of the study to NIHR research portfolio and the support of the Central Research Network (CRN) helped in population of the study to other healthcare sites across England. This resulted in study set up at another hospice in Southeast England in January 2021. Hence, five sites were recruiting for this study which included:

- One palliative care unit of a teaching university hospital.
- One community health services setting.
- Two hospices in the East Midlands.
- One hospice in the Southeast of England.

Although, follow up was maintained with all sites, none of the participants were identified through the community health services setting. The community health services staff acknowledged that they would only give the study documents to potential participants and would not follow up with them. They rationalized this by not influencing participants' decision and to protect their professional relationship with them. Therefore, the final number of recruiting sites was four research sites.

- Participants' identification and contact

Family carers were identified by the research delivery staff or HCPs from the case load files of PwC who were admitted at or used palliative care unit, hospice, community health services or those who used wellbeing and bereavement support. They were firstly approached by the research delivery staff and HCPs to inquire about their willingness to participate in the study and to ensure their eligibility for participation. This was predominantly done by phone calls, since the on-site appointments and consultations were suspended, limited or conducted remotely from March 2020 due to the pandemic that negatively impacted access to potential participants and the recruitment progress. Interested eligible participants were sent a study invitation letter (Appendix 3.1.) and Participant Information Sheet (PIS) (Appendix 3.2.), while allowing a period of time up to a week for the participants to decide if they were willing to participate in the study. Follow up contacts with potential participants were done by the research delivery staff or HCPs and if participants agreed to be involved in the study, their contact details were shared with the researcher for the arrangement of interviews.

Although recruitment was planned through gatekeepers, the emergence of the COVID pandemic resulted in strict regulations for social gathering and visiting arrangements at healthcare settings during the national lockdown and beyond throughout the study recruitment period. This limited the opportunity of research delivery staff and HCPs at the research sites to approach FCs who either would have accompanied PwC in their consultations or attended wellbeing sessions

in full capacity as intended. Therefore, online and social media recruitment were used for improving recruitment progress following the necessary study protocol amendments were made, and approvals were updated (Appendix 4.2.).

4.5.4.b Online and social media research recruitment

Online and social media recruitment is considered an effective approach for getting participants involved in research through disseminating study information to a large scale of potential participants while nonbeing restricted by geographical locations (Benedict et al., 2019, Gorman et al., 2014). In this study, online recruitment was achieved through organisational websites for healthcare research **"People in research"** (https://www.peopleinresearch.org/view-opportunities), **"Cancer research UK"** (https://www.cancerresearchuk.org)" and a specialized participants' recruitment website **"Call for participants"** (https://www.callforparticipants.com)". However, none of the recruited participants were identified through these sources. Social media networks such as Facebook and Twitter were used through sharing the study information through a professional twitter account and the official Facebook page of the hospices (Appendix 3.5.). This was useful for recruitment in this study since two FCs approached the study through a hospice official Facebook page. Three FCs were approached the study through the Intranet of an NHS trust site that originally was responsible for the delivery of the study recruitment through community health services. Two FCs were referred by other FCs who shared the caregiving

with them. FCs who were referred by other FCs or self-referred through the hospice official Facebook page were contacted to discuss their eligibility for participation and discuss the study procedures with them through a phone call likewise, the standard approach of gatekeeper participant's recruitment.

4.5.4.c Participants recruitment progress

The recruitment period extended from September 2020 to June 2021 with the last interview conducted in August 2021. It was noted that recruitment progressed slower than expected with an average of 1-2 participants/month that finally yielded 26 FCs of PwC. This was attributed to the challenges of recruitment during the COVID pandemic as well as the difficulty in recruiting participants in EoLC research. Furthermore, the time limit imposed for recruiting bereaved FCs (i.e., bereaved FCs were approached primarily within the time frame of 3 months up to 2 years of PwC's death) was found impractical and non-helpful that restricted the participation of FCs who were different in the bereavement stages. Therefore, an amendment was submitted to ethics committee regarding participation eligibility criteria (Appendix 4.2.), by which bereavement status was not restricted by a timeline and left open which allowed FCs in different bereavement stages to participate in the study. The benefit of this decision was also realised in the analysis process, since it facilitated the development of salient category regarding the experience of reward or guilt and regret in bereavement which will be explored in Chapter five.

4.5.5. Data collection

Qualitative data collection involves various methods such interviews, focus groups, observation and analysing documents and texts (Bolderston, 2012). The selection of data collection method depends primarily on the research aim and nature of data that will be collected (Duffy et al., 2004, Wimpenny and Gass, 2000). In this study, qualitative interviews were perceived as an appropriate method that aligned with the study aim to explore FCs' experiences about formal support at EoL. Qualitative interviews help to gather rich information about participants' experiences, feelings, and opinions as well as it conforms with CGT traditions (Charmaz, 2014, Patton, 2002). Hence, it facilitates a focused research direction with some sort of flexibility that contributes to the emergence and construction of meanings ascribed to participants' experiences (Wimpenny and Gass, 2000, Charmaz 2001, Duffy et al., 2004, Charmaz, 2014).

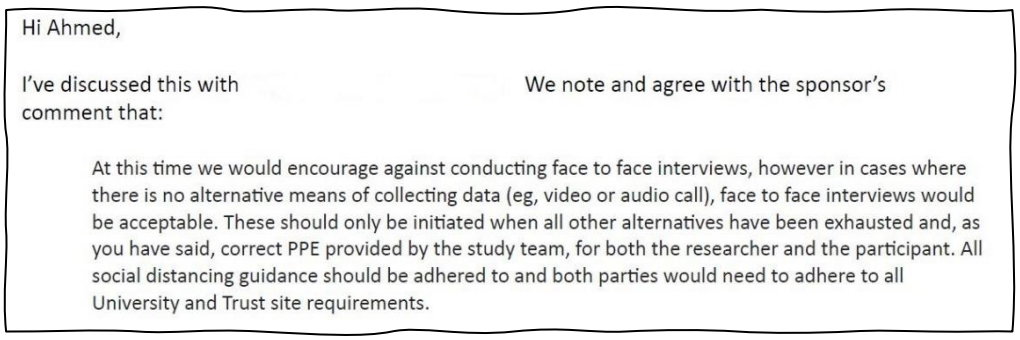
4.5.5.a. Qualitative interview

The interview is described as a focused purposed directed conversation (Charmaz, 2014). In CGT, it starts open to explore topics and experiences of interest to the participants, then it becomes focused on specified topics that could offer theoretical significance to the studied phenomenon (Charmaz, 2014). Therefore, an interview topic guide is necessary that provides a range of open ended-questions with suitable props to direct the interview context and facilitate a systematic approach to explore the studied phenomenon (Patton, 2002, Charmaz, 2014).

In this study, the interview topic guide was developed based on the identified research gaps and the topics arisen in similar family caregiving research (Appendix 3.4.).

Qualitative interviews could be conducted either in-person or remotely with participants' approval. However, in-person interviews are more reliable for capturing participants' nonverbal responses and establishing rapport easily (Shuy, 2001, Muntanyola Saura and Romero Balsas, 2013).

In-person interviews were a preferred interview mode in this study, with a remote interviews option for potential participants who wished to be interviewed remotely. However, prior to conducting the field work, the COVID pandemic unfolded in March 2020 that led to in-person interviews not being permissible due to social gathering restrictions that continued throughout the most of field work period; remote interviewing was the main mode for data collection (Figure 11.) and in-person interviews were considered in very limited occasions.



Hi Ahmed,

I've discussed this with [redacted] We note and agree with the sponsor's comment that:

> At this time we would encourage against conducting face to face interviews, however in cases where there is no alternative means of collecting data (eg, video or audio call), face to face interviews would be acceptable. These should only be initiated when all other alternatives have been exhausted and, as you have said, correct PPE provided by the study team, for both the researcher and the participant. All social distancing guidance should be adhered to and both parties would need to adhere to all University and Trust site requirements.

Figure 11. Email communication withholding face to face interview.

It is reported that remote interviews can be attributed to some research benefits regarding the reduction of research costs e.g. travel costs and time and allowing flexibility for participants in terms of their time and place of interview (Shuy, 2001, Bolderston, 2012). The study participants were given a choice of either phone or audio/video online interviews.

4.5.5.b. Conducting the fieldwork (interviews)

In preparation for conducting the interviews, the researcher contacted participants to discuss their research expectations and any potential concerns. An initial text message or email was sent to participants to introduce myself and arrange a time to discuss the study purpose, PIS, informed consent (Appendices 3.2-3), interview practicalities and answer their questions.

However, I confirmed that no commitments for participation would be granted in the initial contact. This initial engagement was beneficial in developing rapport with the participants and made them feel safe regarding their participation expectations. Following this initial contact, a phone call was arranged usually in the same day or the time that participants found suitable. In this phone call, I went through the research process in detail and arranged a time for interview if they agreed to opt in the study. Consent form was sent to the participant either by post or through email that usually took about three days, so that they could have time to think again about their participation and discuss it with others. The full study regimen is presented in the following flow chart (Figure 12.).

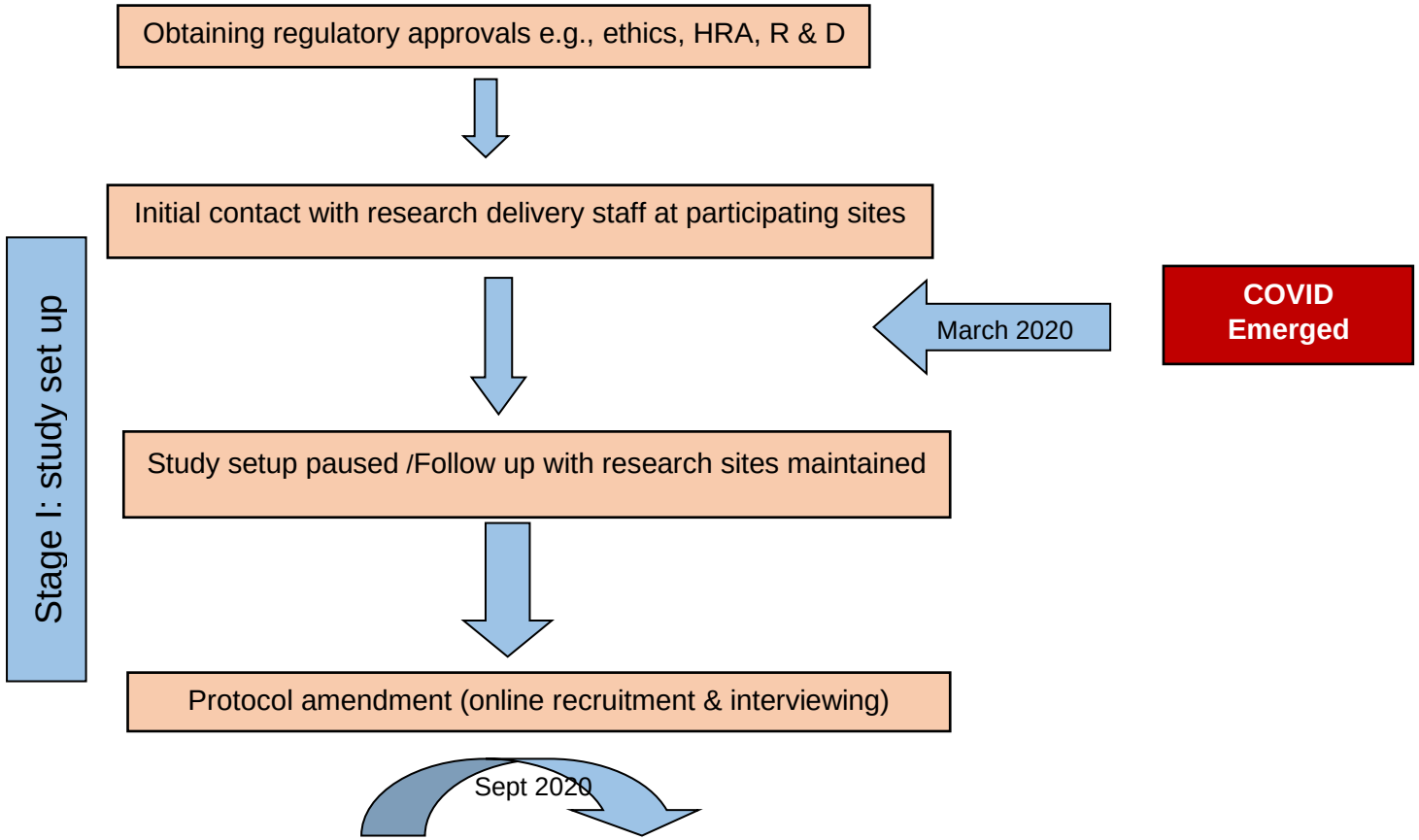
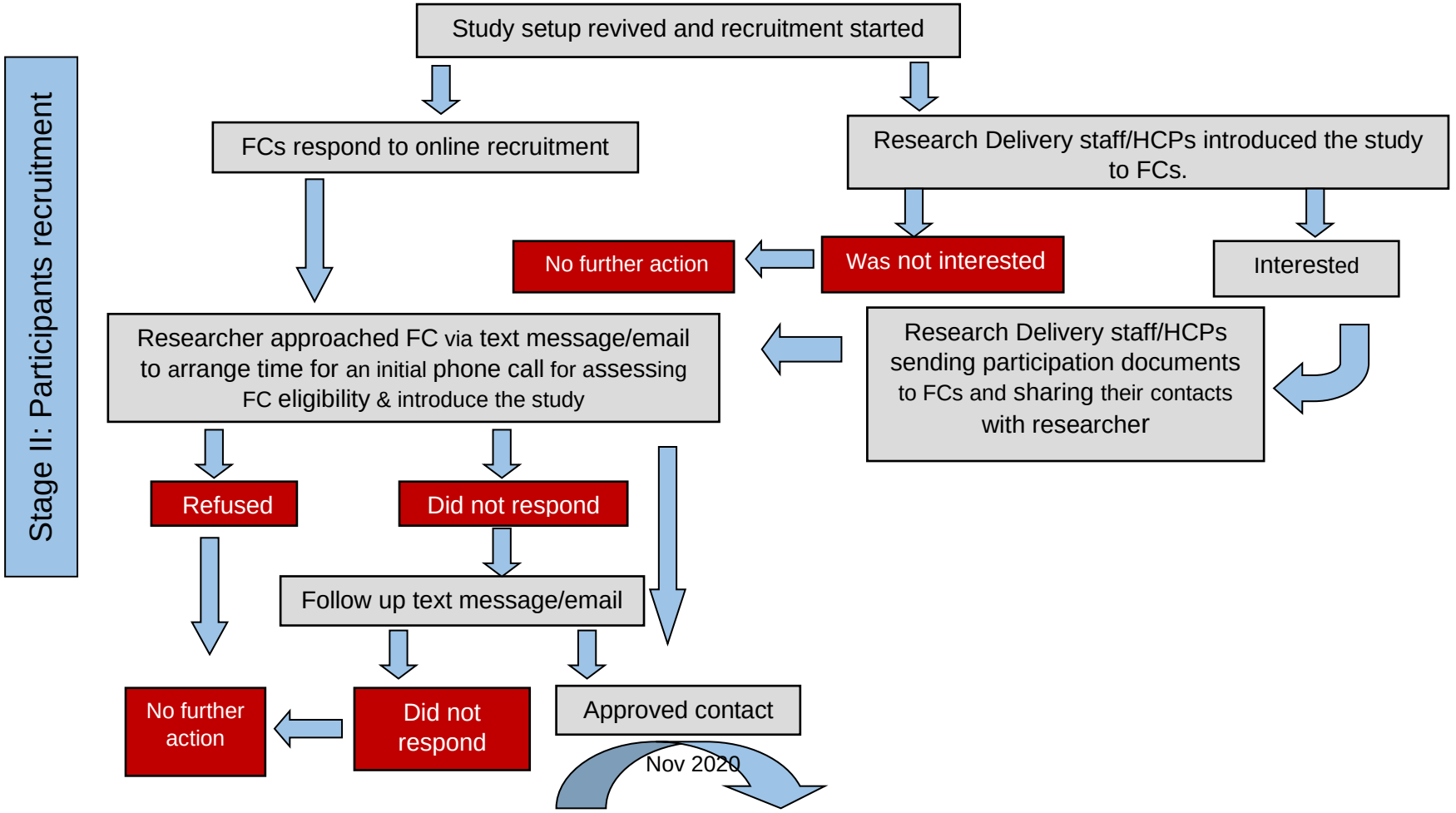
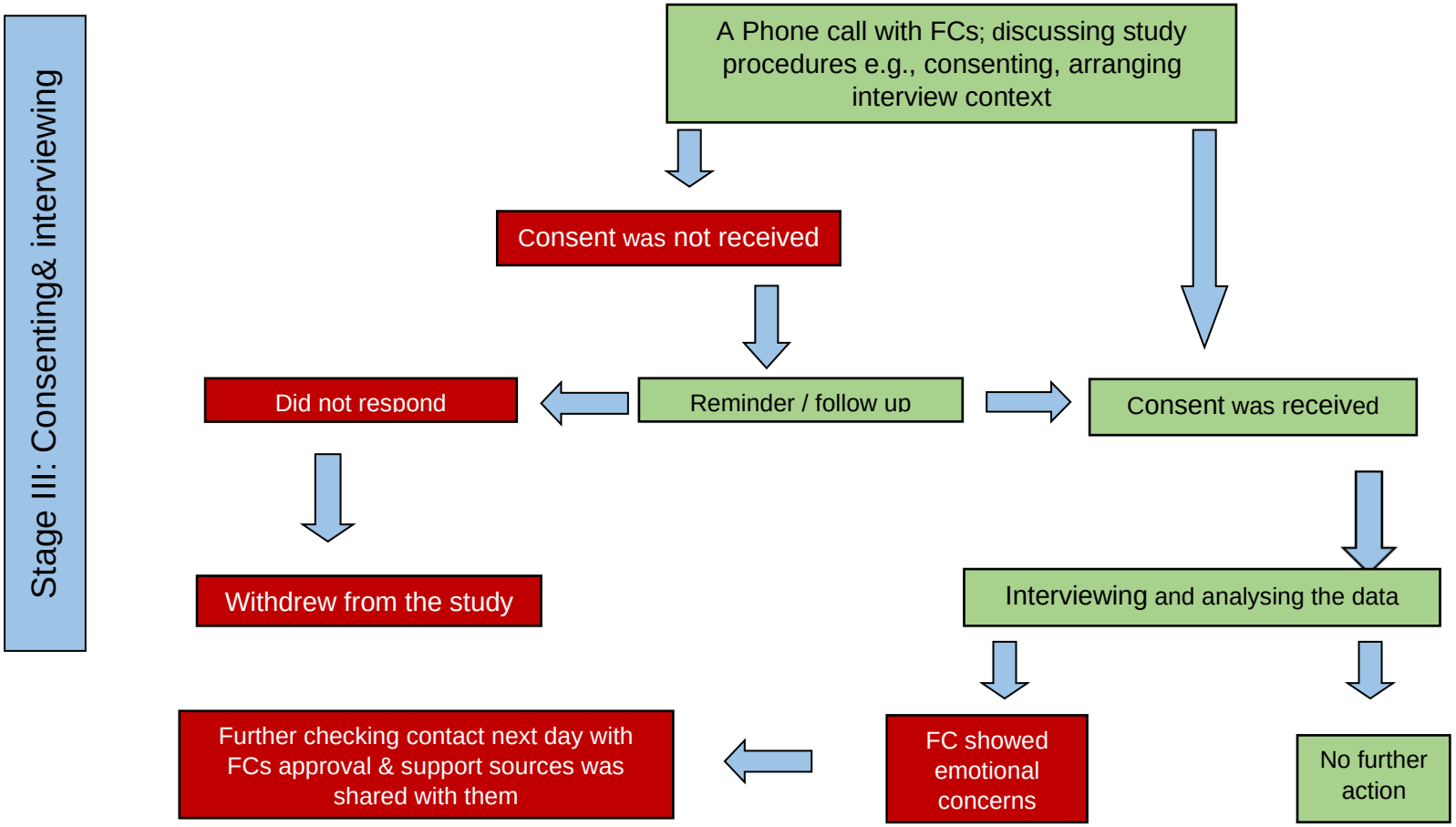


Figure 12. Study regimen flowchart


Stage II: Participants recruitment
Study setup revived and recruitment started
FCs respond to online recruitment
Research Delivery staff/HCPs introduced the study to FCs.
No further action
Was not interested
Interested
Researcher approached FC via text message/email to arrange time for an initial phone call for assessing FC eligibility & introduce the study
Research Delivery staff/HCPs sending participation documents to FCs and sharing their contacts with researcher
Refused
Did not respond
Follow up text message/email
No further action
Did not respond
Approved contact
Nov 2020


Stage III: Consenting& interviewing
A Phone call with FCs; discussing study procedures e.g., consenting, arranging interview context
Consent was not received
Reminder / follow up
Did not respond
Consent was received
Withdrew from the study
Interviewing and analysing the data
Further checking contact next day with FCs approval & support sources was shared with them
FC showed emotional concerns
No further action

Flexibility regarding time and mode of the interview e.g., phone or audio/video call was confirmed to the participants. However, I planned for a maximum of two interviews per week to allow time for listening to the audio recordings and reflecting on the earlier interviews. This helped me in identifying plausible ideas and topics for further exploration in the subsequent interviews. Audio recording of interviews was planned and approved by participants prior to the interview and was documented in their informed consent.

In the planning for the interview day, the topic guide was reviewed and the equipment **"Digital recorder and headset/record adapter"** and software **"Microsoft Teams"** that were used in the interviewing and recording process were checked to ensure a smooth interview progress without interruptions. A digital recorder was used to record all interviews and Microsoft Teams was used to undertake the online interviews. Using the Microsoft Teams platform was decided after consultation with the University research governance and R&D department of the participating sites to ensure using a platform that conformed with the data protection regulations. However, recording, and automated transcription options in MS teams was not used because it was not necessary to record video calls and I considered not recording the video call could make participants more comfortable during the interview. However, this created a dilemma of recording audio-only from a video call interview which was not a supported option by this platform. After thorough internet searching, a headset/record adapter was identified as an option that connects the laptop with the digital record while using the same earpieces.

The interview started with a welcome and thank you statement to FCs, then they were asked about any concerns or queries regarding their participation in the study. They were assured that they could interrupt or stop the interview any time if they felt with emotional burden. After reconfirming their approval for recording, the interview started with an open question about PwC and their caregiving responsibilities. Then, the interview progressed with more specific topics in the interview guide (Appendix 3.4.) while using prompts to explore unclear meanings and interesting leads in the participants' narratives. Furthermore, the identified analytical ideas from the previous interviews were documented to inform and guide subsequent interviews which would help in developing theoretical categories (Charmaz, 2014).

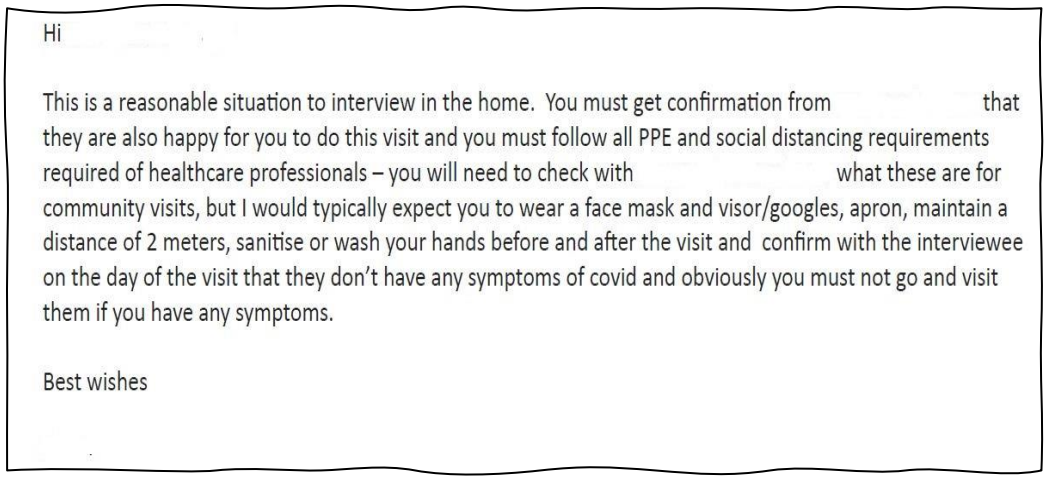
Some challenges were encountered during the interviews; however, strategies were implemented to adapt to these challenges. For instance, poor quality phone network and disconnection occurred, whilst follow up calls were made simultaneously, and interview was continued. Some participants experienced technical difficulties regarding the set-up of the online meetings and a step-by-step guide was provided to support them through a phone call during the day of interview. Establishing rapport with participants in remote interviews could be challenging due to limited personal interaction and nonverbal communication (Bolderston, 2012). However, the initial contact through messages, emails and calls about the study procedures was considered as an icebreaking approach that facilitated the professional research relationship and establishing rapport. Furthermore, participants were

informed about what was expected from them and granted control over the interview environment e.g., opting out from any question they felt uncomfortable to facilitate developing emotional security during the interview. Although, nonverbal cues such as facial expressions could be difficult to be tracked in remote interviews (Muntanyola Saura and Romero Balsas, 2013), an attentive listening approach in audio calls and the visual component in video calls facilitated identifying some of these cues such as the tone of voice that might indicate distress or sadness (Janghorban et al., 2014).

Some interruptions occurred during the interviews such as network breakdown, response to other family members or a pet which could have disturbed the interview flow. However, I used this to give FCs the choice of a break or to reschedule the interview to another time. None of the participants required this but it prompted me to keep attention to the time and trying to be more focused on specific topics during the remaining period of the interview. However, some interviews needed to be rescheduled several times due to the emergent commitments of FCs before they started the interview. The flexibility associated with remote interviews allowed this to happen which made participants feel not rushed and facilitated their participation (Janghorban et al., 2014).

Remote interviews were problematic with some categories of participants such as older adults and people with a hearing impairment, experienced in two interviews. One interview was conducted involved a FC with a hearing impairment who needed reiteration of some questions that were being asked. Therefore, the attendance of the PwC was

requested by the FC to repeat unclear points. This was addressed in the planning phase of the study where an option for PwC attendance during the interview could be approved following their signing an informed consent. However, it was indicated that only FCs' narratives would be used in the data analysis. Another interview was conducted with an older FC with a hearing impairment. However, it was requested to be done in-person after the COVID pandemic restrictions were relieved in April 2021. A risk assessment was done (Appendix 6.) and the University and research site approvals were gained for this exceptional in-person interview following the home visit health precautions e.g., wearing Personal Protective Equipment (PPE) and social distancing (Figure 13.).



Hi

This is a reasonable situation to interview in the home. You must get confirmation from that they are also happy for you to do this visit and you must follow all PPE and social distancing requirements required of healthcare professionals – you will need to check with what these are for community visits, but I would typically expect you to wear a face mask and visor/googles, apron, maintain a distance of 2 meters, sanitise or wash your hands before and after the visit and confirm with the interviewee on the day of the visit that they don't have any symptoms of covid and obviously you must not go and visit them if you have any symptoms.

Best wishes

Figure 13. Resuming in person interview email communication

The sensitive nature of EoL interviewing was another field work challenge encountered in this study. For instance, I had to be vigilant about the language used during the interview to avoid unnecessary emotional distress to FCs.

Therefore, I spoke less on certain occasions and used reflection and summarising strategies more often which was useful in checking my interpretations with FCs. Furthermore, I tried to conclude the interview positively by shedding the light on the positive instances that FCs talked about during the interview whenever possible (Charmaz, 2014). On some occasions, participants became emotional during the interview. However, a protocol for handling emotional difficulties during sensitive interviews was in place and was followed accordingly (Appendix 7.). For, instance, participants were offered a break and had the opportunity to pause, reschedule or end the interview. Similarly, some participants went beyond the focus of the interview and told irrelevant stories. If this occurred, I tried to be attentive to what they said to make them feel appreciated and gently returned to the topic that was being discussed.

In the concluding phase of the interview, a summary of topics and views that had been explored during the interview was discussed with the participants as a source of informal member checking to enhance the study rigour which will be discussed in detail in Section 4.5.8. Furthermore, participants were asked if they would like to add anything to what have been discussed. Then, socio-demographic characteristics of participants such as age and working status were discussed with them. Socio-demographic questions could be troublesome for some research participants who would find it intrusive and embarrassing so that leaving this kind of questions to the end of interview could help sustaining the rapport (Hughes et al., 2016). In this study, I found delaying these questions was useful; if participants preferred not to answer any of them,

it could not affect the progress of the interview process. The interview was closed by appreciating FCs' valued contribution and they were asked to reflect on their participation experiences. Participants' reflection on the interview was necessary to check if they experienced any emotional concerns as a result of their participation (Figure14.). However, participants were pleased about their participation and found it beneficial for various reasons such as a giving back attitude and methods of helping others through developing insightful services' improvement recommendations based on their experiences.

"The interview has been calm (and)got a lot of my chest to be honest with you" (Int 01: Elizabeth cared for her brother)

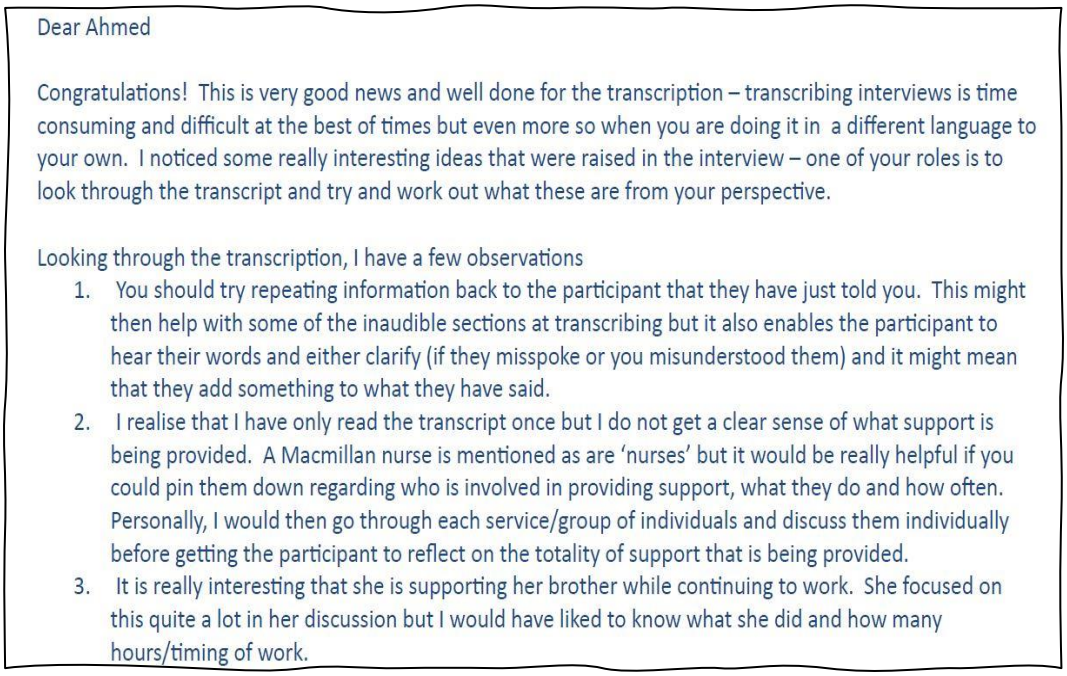
"I just want to help people and give back because we've been given so much. If I can do anything that would help other people in our situation, then that's why I have done it" (Int 11: Maria cared for her husband)

Figure 14. FCs reflection on interview

Further contact was occasionally needed in the following day with two FCs who showed emotional concerns during the interview and a list of support services was shared with them (Appendix 3.6.)

Each interview recording was given a serial number and stored in a password protected University computer for preparation for transcription. Seven interviews were transcribed by me to promote familiarity with the interview data that could enhance the analysis process. Then, a professional transcriber was used to transcribe the rest of interviews to save time and keep on track with the analysis process, a non-disclosure agreement was in place (Appendix 5.). Each transcript was labelled with a serial number, revised, checked with audio recording, and anonymized.

The first three interviews were reviewed by the supervisory team to check the quality of interviews. They also offered recommendations to be considered in the subsequent ones; the following excerpt was supervisor feedback on the first interview (Figure 15.).



Dear Ahmed

Congratulations! This is very good news and well done for the transcription – transcribing interviews is time consuming and difficult at the best of times but even more so when you are doing it in a different language to your own. I noticed some really interesting ideas that were raised in the interview – one of your roles is to look through the transcript and try and work out what these are from your perspective.

Looking through the transcription, I have a few observations

1. You should try repeating information back to the participant that they have just told you. This might then help with some of the inaudible sections at transcribing but it also enables the participant to hear their words and either clarify (if they misspoke or you misunderstood them) and it might mean that they add something to what they have said.
2. I realise that I have only read the transcript once but I do not get a clear sense of what support is being provided. A Macmillan nurse is mentioned as are 'nurses' but it would be really helpful if you could pin them down regarding who is involved in providing support, what they do and how often. Personally, I would then go through each service/group of individuals and discuss them individually before getting the participant to reflect on the totality of support that is being provided.
3. It is really interesting that she is supporting her brother while continuing to work. She focused on this quite a lot in her discussion but I would have liked to know what she did and how many hours/timing of work.

Figure 15. Email feedback on the first interview

This feedback obtained helped me in improving the quality of subsequent interviews and to focus questions on interesting points identified. By the end of data collection period, twenty-five intensive interviews were conducted. All interviews were done remotely with the exception of one was in-person. Remote interviews included 16 phone interviews and 8 online Microsoft Teams interviews (2 audio only calls /6 video calls). The duration of the interviews lasted between 30 to 120 minutes. All interviews were a single one to one interview except two interviews. One of them was dyadic in which PwC attended the interview

with FC. The other interview was conducted with a couple of FCs who cared for the same PwC and preferred to be interviewed together.

4.5.6. Data analysis

Grounded theory suggests that data analysis should be intertwined with data collection to inform further data collection activities (Duffy et al., 2004, Charmaz, 2014). Therefore, in this study transcription and analysis started after the first interview to identify plausible ideas and leads that were needed to be explored in further interviews. Data coding is the first analytical step in grounded theory research (Bradley et al., 2007, Charmaz, 2014, Elliott, 2018). Coding is assigning each segment of data a short name or statement that describes and summarises topics, and issues of concerns that each piece of data explores (Bradley et al., 2007, Gill et al., 2008, Saldaña, 2013, Maz, 2013, Charmaz, 2014). The process of coding could be done manually or by using a computer software (Gill et al., 2008, Sutton and Austin, 2015). In first instance, I used a computer data coding software (Nvivo 12.0) to facilitate a structured and retrievable approach for data analysis process (Elliott, 2018). Whilst, the ultimate use of data coding software could make the analysis more superficial, and the researcher could lose interaction with the data (Elliott, 2018). Thereby, I perceived that I should not be confined to a software platform throughout the whole process of analysis to ensure engagement with data that could in turn deepen the analysis. A hard copy of developed codes with supporting participants' narratives was prepared to facilitate the interaction with the data and constant comparison processes. This step facilitated refining codes and identifying the

relationship between the developed categories using highlighters and annotations.

The analysis process involved two main coding practices; initial and focused coding to facilitate developing theoretical categories that contribute to theory development (Charmaz, 2014). An important feature of initial coding is being open to the theoretical leads which could be achieved through line by line coding practice (Charmaz, 2014). Going line by line throughout the data enables the researcher to be open to nuances and track the implicit meanings that would shape the analysis directions (Charmaz, 2014). In this study, initial coding was done through open line by line coding without any attempts to sort or group the developed codes. Initial codes were kept very close to the participants' narratives to preserve their voices in the analysis. Furthermore, codes were developed in gerund format whenever possible. This approach helps in identifying the actions and processes in the data and being close to it (Glaser, 1978). While engaging in initial coding, the constant comparison process was applied throughout the analysis to identify similarities and differences in the data. This was done through comparing different segments in the same interview and between different interviews; comparing data to codes, code to other codes, codes to categories and comparing between categories which helped in the development of codes and categories (Glaser, 1967).

After the tenth interview, several initial codes were generated and reviewed to exclude non-telling codes and combine repetitive codes that had similar meanings. Furthermore, I explored the more frequent codes

that could have salient theoretical directions. This process was described by Charmaz (2014) as focused coding which is considered the second major analytical stage in CGT. In this stage, the researcher is looking for the most frequent codes that could be developed into conceptual abstract categories (Maz, 2013). In this study, it was done through frequent reading of the interviews' transcripts and recoding the initial codes (Charmaz, 2014). Furthermore, I referred back to the coded participants' narratives in the original transcripts to get the sense of the whole context and compared codes and categories with the relevant data. A continuous process of data inquiry throughout the analysis process facilitated going beyond the descriptive meanings to more abstract level. However, I usually kept these developed categories open for refining while being compared with other participants' narratives. An example of coding and analysis process is illustrated in the following (Table 4.). This process resulted in developing three major theoretical categories which will be explored in detail in Section 5.4.

Table 4. Coding and analysis process

Theoretical category	Sub-category	Dimension	Assigned codes	Participants narratives
Living in the chaos of caregiving.	Dealing with competing responsibilities.	Struggling with combining work with caregiving.	Struggling with work / Competing multiple responsibilities/ being in the conflict between various roles and identities/ lacking workplace support.	*"I go to work I am struggling a bit there because I would like time off and there was no cover and I do not think my boss is brilliant understand me about it which I get quite annoyed because she knew about this since July …". (Int01: Elizabeth; cared for a brother).*
Interacting with formal support.	Getting proper support at the proper time.	Timeliness of support.	Experiencing delayed support; feeling helpless and lonely.	*"We were very alone that night and it was long night it was started my mothers' pain Saturday 11:00 o'clock in the morning and we did not get actual help out until four o'clock in the early hours of the next morning by the time…." (Int08: Emily; cared for her mother)*
Feeling rewarded versus guilt and regret.	Spending quality time.	Experiencing the reward of spending a quality time.	Having good/bad caregiving memory/ spending quality time.	*"I think the rewarding part was we managed to spend all that time together, which … yes he was very poorly but that was good". (Int07: Jennifer cared for her husband)*

Memo writing is a helpful strategy for documenting the researcher's accounts of the analysis process; ideas about the development of codes and categories; the relationship between them; and making inquiries into the data (Glaser, 1998, Maz, 2013). In this study, initial memos were written in a descriptive style to explain what was happening in the data and the important concerns that FCs brought into the interviews (Figure 16.).

Memo and analytical thoughts emerged from Int02: (Barbara; a bereaved FC cared for her mother Margert)

While talking about home support and Barbara went back retrospectively, she found herself spent much time in household tasks that probably would have spent with her mother, so the question is they did not use the community carers? Or they did not know about their existence? But what makes them feel they did not need support?

Despite Barbara realised she needed support with household tasks to have free time to spend with her mother for instance to review the photos album. It was over because she did not consider this at that time so the regret would be here an emerging feeling.

Figure 16. Descriptive memos

Then, memos were more precise and went beyond the description into defining the salient categories dimensions and describing how the identified concepts were interrelated (Figure 17.).

Later memo about sharing the caregiving concept; Approaching caregiving as a family.

Sharing the burden as a family. In this concept, FCs shared caregiving together through sporadic offer for doing tasks or forming a team through arranging different tasks between them in rotas that lessened the burden and some of them were satisfied about that such as (FC13; Olivia and FC14; Debra). However, others did not have this sort of informal support which affected their normal routines. This related in some instances to Covid (FC16; Stephanie) that limited the chance of having family and friends to help and support. Others did not received help from other family members and referring it as a person's choice to help (FC21; Christina). This created a significant distress and burden on FCs when they carried out the responsibility alone.

Figure 17. Analytical memos

After the major theoretical categories were developed, a description of these categories that explained their theoretical properties was provided. Moreover, a further process of theoretical sorting and diagramming was conducted to facilitate displaying the theoretical links between the developed categories (Charmaz, 2014). Theoretical sorting in this study involved a review of the theoretical categories, investigation of the relationships between them, and exploration of a logical structure that could describe the overall FCs experiences (Charmaz, 2014). Furthermore, diagrammatic illustrations of relationships between theoretical categories were developed (Figure18.). This helped in refining the whole theoretical interpretations and developing the theory with the relevant theoretical model illustration presented in the findings chapter at Section 5.4.

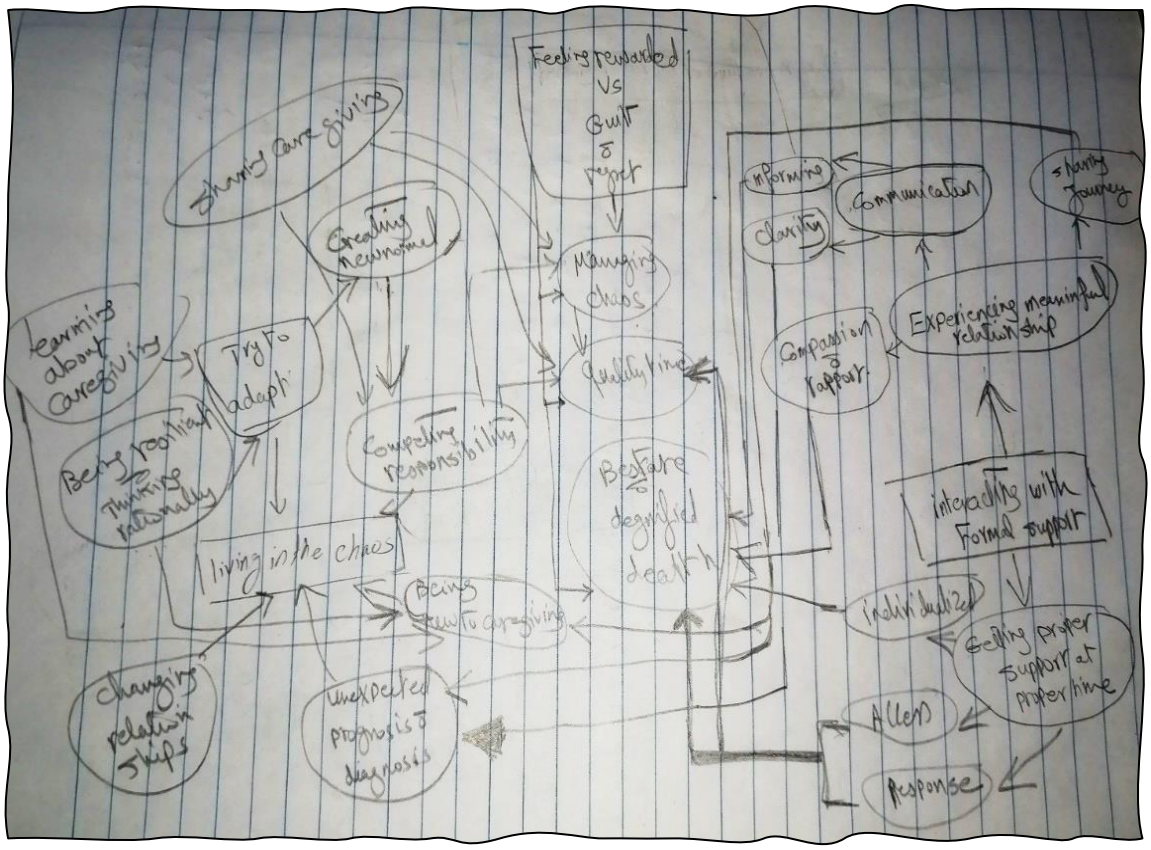


Figure 18. Diagrammatic illustration of relationships between categories and sub-categories

4.5.7. Ethical considerations and regulatory approvals process

Qualitative research deals mostly with human life experiences so that it should be ethically sound (Orb et al., 2001, Cohen and Crabtree, 2008). This necessitates carrying out research that is conforming with the values of humanity, respect, empathy, honesty and benefit (Cohen and Crabtree, 2008). Ethical aspects in research involve issues regarding the research conduct and data processing such as informed consent, data confidentiality and participants' benefits over the risks (Lipson, 1994, Creswell, 2018a). These ethical aspects were considered in this study from the planning phase and throughout the study process.

In the planning stage, I was aware of the emotional sensitive nature of this research topic exploring EoLC experiences of FCs who might be

struggling with caregiving responsibilities or emotionally suffering due to the PwC's illness or their bereavement. Therefore, sampling the participation documents and review by the PPI group prior to data collection was perceived essential as highlighted earlier in Section 4.5.1. This helped in screening the language suitability of study documents (e.g., invitation letter, PIS, consent form) and interview questions to EoLC context so that it would not trigger any emotional concerns.

Application was made to the University Research Governance and NHS local Research Ethics Committees (REC) in Dec 2019. A formal ethics meeting with South Central - Oxford C Research Ethics Committee was attended on January 2020. A favourable opinion and HRA approvals were received in March 2020 with a reference number (20/SC/0029) (Appendix 4.1.). However, due to the pandemic restrictions on social gathering that affected the participants' recruitment process and suitability of in-person interviews, some amendments were introduced to the study procedures in response to challenges imposed by the pandemic such as the introduction of online recruitment and remote interviewing and informed consenting. Therefore, an ethics amendment was submitted and approved by the ethics committee in July 2020 (Appendix 4.2.)

Informed consent is a crucial feature of conducting an ethical qualitative interview research (Orb et al., 2001). It refers to participants making fully informed decisions about the study different aspects and deciding voluntarily whether or not to take part in the study, confirming their right to withdraw at any time without any negative consequences

placed upon them (Orb et al., 2001). The informed consent process in this study involved firstly, sending invitation letters and PIS to FCs by the research delivery team at the participating sites or by the researcher if they were approached through online recruitment. Then, sufficient time was given to FCs to decide about their participation in the study which ranged from 24hrs to a week. During the initial phone call the study procedures were explained in detail while confirming the voluntary nature of participation. Any participants' questions were answered, and informed consent was explained.

By transferring the interview procedure into the remote mode, gaining consent was challenging to some extent. The consent form was posted one week before the interview then I followed up with FCs until they signed and posted it again in the pre-stamped envelope that was provided in the study document pack. This process lasted about two weeks, therefore, in some instances I asked FCs to sign, scan and email the signed consent form to start the interview promptly until the posted hard copy was received. Some participants preferred to only sign an emailed consent which sometimes was challenging for them to do on computer software. On this occasion, a hard copy of informed consent was offered and posted to them. A supplementary consent for PwC was provided in case of they wished to attend the interview which happened in one instance.

Other ethical principles that were ensured in this study were the participants' confidentiality and anonymity (Orb et al., 2001). Finding suitable ways of interview recording that conformed with the ethical and

institutional regulation of handling confidential data was challenging. Since, I had to use a digital audio recorder rather than using a third-party software application to ensure the confidentiality of the participants' information. Furthermore, online interviews were needed to be conducted through the University and NHS approved platform **"Microsoft Teams"**. This platform records either audio or video calls. This created a dilemma of how to record the audio only in the case of video call conversations to conform with the conditions of study ethics approval that specified audio recording only. Using headset/record adapter that connected the computer with the digital recorder resolved this issue.

Another aspect of ensuring participants' confidentiality was keeping interviews' audio recordings and transcripts securely in a private folder in a password protected University Laptop following the University of Nottingham data protection and data retention policy (The University of Nottingham, 2018a, The University of Nottingham, 2018b). Furthermore, FCs' personal contact details were kept separate and secure from other study documents e.g., transcripts, field notes and memos.

Keeping participants' anonymity involved making sure that FCs could not be identified through their names, place of residence, or any other personal characteristics (Orb et al., 2001). A trusted provider was used in the transcription of a number of study interviews and a non-disclosure agreement was in place (Appendix 5.). The audio recordings and transcripts were given serial numbers annotated with the interview date rather than using any participants' personal details. The transcripts were

revised thoroughly to remove any identifying information, such as names, places or organizations and pseudonyms were used instead of participants names in reporting study findings.

Lastly, safeguarding of participants and researcher was another important ethical aspect of this study. EoLC research could be emotionally distressing to research participants; however, positive experiences were also reported as a result of research participation (Bentley and O'Connor, 2015). In the planning for ensuring participants' and researcher safety, a study risk assessment was done, and potential risks were identified (Appendix 6.). Conducting emotionally sensitive interviews with research participants was identified as requiring skills to deal with stressful conversations. My existing skills as a professional nurse and a researcher who conducted similar research interviews during my master's thesis facilitated dealing with sensitive interviews. Additionally, further formal training for EoL communication **"Dying to communicate course"** was taken prior commencing the study through a specialized palliative care unit training department. Although this was a palliative care practice training, it signposted me to the important communication skills such as attentive listening and reflection. Furthermore, it involved a personalised role play scenarios that illustrated how to handle difficult emotions such as crying that could have been arisen during the research interview.

Furthermore, strategies were implemented to minimise the potential distressing impact on FCs. For instance, it is suggested that the minimum period that should be considered when interviewing bereaved family

members is three months post bereavement (Sekelja et al., 2010). Therefore, the interviews were planned to be conducted following this recommendation whenever possible to allow for psychological healing as well as facilitating better recalling of experience. However, some FCs' caregiving status changed in the period between when they were approached and their actual participation. In this case, they were given the choice either to wait or have the interview. Some FCs preferred to be interviewed within this time frame, since they felt able to participate and wanted to talk about their experience. Bentley and O'Connor (2015) conducted a qualitative study with bereaved FCs of people with motor neuron disease and cancer exploring the suitable time for involving bereaved FCs in EoLC research. They concluded that FCs should be freely able determine their own ability to participate in EoLC research preferring to be interviewed soon after the death of their relative to recall the experience effectively (Bentley and O'Connor, 2015).

Another safety strategy involved adopting a distress protocol for the qualitative interview to ensure the emotional safety of FCs, in which they were given the choice to pause or end the interview at any time they felt distressed (Haigh and Witham 2015) (Appendix 7.). In the conclusion phase of the interview, FCs were asked about their feelings and if emotional concerns were identified, a list of available counselling services was shared with them (Appendix 3.6.), and an optional follow-up contact (i.e., text message) was made upon their approval to check on them. Similarly, there was the potential for the researcher to experience emotional upset while researching sensitive topics, a

researcher distress protocol was in place to deal with possible emotional concerns (Haigh and Witham 2015) (Appendix 7.). Furthermore, having a regular debriefing sessions with supervisors to reflect upon interviews, keeping a reflexive diary about my feelings and conducting no more than two interviews per week helped to deal with the experienced emotional distress (McCosker et al., 2001, Sivell et al., 2019).

A further safety concern was raised due to the emergence of COVID pandemic. One interview was conducted in-person at the participant home when COVID social gathering restrictions were relieved. For the purpose of participant and researcher safety, COVID vaccination status was confirmed for both parties and the universal health precautions for home visiting during the pandemic were followed such as wearing P.P.E and social distancing. Although, this could have imposed some psychological barriers in building rapport, the reasons for adopting these procedures were explained and accepted by the participant and rapport was established effectively. The University of Nottingham lone working strategy and the Social Researcher Association (SRA) code of practice for researcher's safety were followed accordingly due to concerns regarding conducting interviews in the participant's home (The University of Nottingham, 2012, The social research association, 2012).

4.5.8. Rigour and trustworthiness

Rigour and trustworthiness are important interchangeable concepts used for describing the quality of qualitative research (Smith and McGannon, 2018, Cypress, 2017). Study rigour is defined as the ability to conduct a research study that is carefully planned, accurate, and

precise; this is achieved through the robustness of the study design to answer the study questions and achieve its aims (Cypress, 2017). Generally, robust qualitative research is expected to be ethical, clearly described and reported and using rigorous research design (Cohen and Crabtree, 2008). Trustworthiness was first described by Lincoln (1985) as a way to develop the rigour for qualitative research. It contends the degree of confidence and trust that would be incurred by a research study through representation of authentic and trustworthy findings (Cypress, 2017, Connelly, 2016). This enables the readers to establish their confidence in the study findings to apply the policy and practice recommendations that derived from this study (Hadi and José Closs, 2016). Lincoln (1985) argued that trustworthiness of qualitative research is established through four main criteria which are described in the following (Table 5.).

Table 5. Trustworthiness in qualitative research (Korstjens and Moser, 2018, Cypress, 2017, Connelly, 2016, Lincoln, 1985)

Concept	Interpretation	Strategies used to establish the criteria
Credibility	It refers to the degree of confidence in the study findings and that the reported findings are based on the participants' views.	-Reflexivity. -Informal member checking. -Debriefing.
Transferability	It describes the ability to translate and transfer the study findings to be applied in other contexts with other participants.	Thick description.
Dependability	It refers to the notion of findings stability overtime and different conditions.	Audit trail.
Confirmability	It describes the extent to which the findings are consistent, match the participants' views, and can be replicated by other researchers.	

Several strategies are suggested to promote the rigour and trustworthiness of qualitative research and it is recommended that at least two of these strategies are used to establish study rigour (Creswell, 2018a, Lincoln, 1985, Hadi and José Closs, 2016). The selection of these strategies depends on the nature of the study and the research design (Korstjens and Moser, 2018). In this study, five strategies were perceived valuable and applicable to the study context. These strategies included reflexivity, informal member checking, debriefing, thick description, audit trail (Korstjens and Moser, 2018). Keeping reflective notes is a crucial aspect in the process of establishing qualitative research credibility (Noble and Smith, 2015, Connelly, 2016). Reflexivity is defined as critical evaluation of ones' own impact as a researcher on the research process and relationships; this involved being reflective about personal preferences, biases, thoughts and relationship with the study participants that could have impacted their responses (Korstjens and Moser, 2018). Self-reflection was started in study planning phase and continued throughout data collection, analysis and writing up. Developing field notes and theoretical memos in data collection and analysis processes facilitated the reflexive instance and made my justification for certain study directions clearer such as recruitment decisions, the continuation of data collection and the development of theoretical categories.

Member checking is another strategy for establishing study credibility and confirmability (Connelly, 2016, Hadi and José Closs, 2016, Noble and Smith, 2015). It involves checking participants' interpretations and views regarding the study findings and conclusion (Noble and Smith,

2015). Lincoln (1985) identified two forms of member checking that includes informal and formal member checking. Informal member checking involves activities that could be done during the data collection process such as summarising at the end of interview to identify participants reactions; this was done routinely during and after the present study interviews. The plausible ideas of one interview could be checked with other interviews which was achieved in this study (Lincoln, 1985). Formal member checking involves inviting participants to discuss and comment on the study findings and developed interpretations (Lincoln, 1985). However, several issues made formal member checking problematic and less valuable in this study. For instance, considering that knowledge and perceptions are socially constructed, the time elapsed between data collection and analysis and the time planned for doing formal member checking could impact FCs' views and interpretations, since they could find their present experiences were not aligned with what they described previously (Smith and McGannon, 2018). In other words, some FCs in the study became bereaved after conducting the interview, so that their interpretations and experiential memory could have been affected by the emotional trauma of the bereavement or the end of the caregiving journey. Ethical responsibility and participants' wellbeing are also paramount which made me to dislike using this strategy due to the sensitive nature of the study that could evoke emotional trauma when findings and experiences were reiterated (Sparkes and Smith, 2014).

Debriefing is another strategy for establishing study rigour (Connelly, 2016). It is described as a critical discussion with an expert qualitative researcher to reflect and advise on the data collection and analysis processes (Hadi and José Closs, 2016). Regular debriefing sessions were conducted with my supervisors to discuss the planning for data collection, plausible ideas and themes that could be explored during the subsequent interviews. Debriefing also continued throughout the analysis process to critically evaluate the developed categories until theory was developed. This process was important to ensure that developed categories were grounded on the collected data and the theory is logical and comprehensible to others (Hadi and José Closs, 2016, Cohen and Crabtree, 2008)

Additionally, the documentation of the data collection and analysis process and related decisions are crucial to establish trustworthiness in study's findings and conclusion which are achieved through a transparent audit trail (Hadi and José Closs, 2016). An audit trail is a clear description of research steps from the beginning of the study until the reporting of findings (Korstjens and Moser, 2018). In this study, I started to document the process of recruitment and data collection in my research diary which helped me to clearly report the study design and methods section. This could enhance the study dependability and confirmability (Connelly, 2016).

Lastly, the thick description of the study context is a strategy for establishing research rigour through providing a mean for judging the possibility of transferability of findings to other contexts (Connelly, 2016).

This is also important to determine the feasibility of application of the research recommendations to other similar settings (Hadi and José Closs, 2016). In this study, thick description was achieved by discussing a detailed information of the study context such as setting, participants' characteristics, fieldwork, and data analysis processes.

The evaluation of the rigour of this study was conducted at the end of research process to report on its strengths and limitations using a comprehensive evaluation tool **"The framework for assessing qualitative evaluation tool"** (Spencer et al., 2004) (Appendix 8.). Given that the grounded theory approach has distinct methodological features, and the end product of this design is a development of a substantive theory, certain criteria were suggested by Charmaz (2014) for judging the quality of grounded theory studies that included four items; credibility, originality, resonance, and usefulness. A detailed discussion of the evaluation process and relevance of these concepts to this study is reported in Section 7.5.

4.5.9. Reflexivity

Reflexivity is a key aspect of qualitative research that involves a description of the influences exerted by the researcher's personal and professional characteristics and perceptions, the researcher-participants relationships and contextual background on the whole research process (Engward and Davis, 2015, Korstjens and Moser, 2018). Grounded theorists should be reflexive about every stage in the research process to enhance the study rigour and trustworthiness (Engward and Davis, 2015, Dodgson, 2019, Barrett et al., 2020). Researcher reflexivity in this

study was discussed regarding five aspects which included developing study interest and design, researcher-participants relationship and researcher's positionality, engaging in field work, interpreting the qualitative data, and writing the study report (Horne, 2011).

In this study, my previous professional experience as a nurse dealing with PwC and their families shaped my interest in exploring their suffering and the physical and emotional struggle they could experience as a result of advanced terminal illness. Additionally, being a witness to family caregiving for a frail person at home until EoL triggered my interest in exploring how FCs are supported during this process. By combining these two perspectives, the interest for exploring experiences of FCs of PwC at EoL was developed. Furthermore, a review of published research regarding this topic was conducted as a part of the thesis (Chapter three); this helped in identifying research gaps in the theoretical understanding of the experiences of FCs with support at EoL. The emergence of the pandemic raised another question in my mind about how services could respond to FCs' support needs during this unprecedented time. Although, I was disappointed about the impact of the pandemic delaying the recruitment process, I realised that this crisis could add a new study perspective and contribution to the knowledge.

The rationale for choosing the present design and methods was mainly due to its fit to the study aim and objectives, a detailed justification for the methodological approach was discussed in previous Sections 4.2-4 & 4.5.5-6.

The researcher's position relative to the studied phenomenon and context is known to have a significant influence on the qualitative research process particularly in healthcare research where adopting a researcher only position could be challenging (Barrett et al., 2020). In this study, my self-representation to the gatekeepers as an insider of the healthcare system, (Nurse researcher exploring a health service-related experiences), helped me to initiate a common interest in the improvement of services; this supported the study recruitment activities. Similarly, being an insider with caregiving experience helped me to understand FCs' position and make sense of their experiences through having a common ground and interest which facilitated our conversations.

Being a nurse with assessment and observation skills, and a passion for helping and caring for people, made me vigilant about not inducing any emotional distress on FCs as a result of the participation. Being an academic nursing teacher prompted me on some occasions to signpost FCs to support services that could be available to them; this helped me while exploring their views or expectations about support services. Being a non-UK international conducting research in the UK context made me feel concerned for several reasons. Firstly, the ability to understand FCs' culture and local expressions could influence the quality of data interpretation. However, reflecting, seeking clarification and internet searching about vague expressions helped me in meaning-making. I also had the challenge of exploring FCs' experiences in healthcare system unfamiliar to me. I found it was very important to understand and study

the UK health system and EoLC services to be able to discuss their aspects with FCs. Reviewing multiple governmental and charity reports about healthcare services, caregiving and EoLC (NICE, 2015a, Ipsos MORI and Macmillan Cancer Support, 2011, Department of Health, 2008), as well as supervisors' consultations, helped me to develop a clear understanding of the services' structure and their delivery; this facilitated my discussion with FCs during interviews. Lastly, I perceived that being a cultural outsider could affect rapport and trust with FCs. However, I found that UK context of diversity and inclusion, plus being introduced by the gatekeepers to FCs, facilitated establishing rapport and trust.

Other aspect of reflexivity process was keeping field notes for regular recording of observational data during fieldwork to report on the social context and interactions that happened during data collection activities (Montgomery and Bailey, 2007). It also accounts for the researcher's reflections and feelings experienced while collecting data in the field (Patton, 2002). Following the interview, field notes were documented whenever necessary to record; my observations of nonverbal communication such as the tone of voice and hesitations; FCs' reactions to questions; and the main points and concerns that were discussed during the interview. These field notes were used in identifying strengths and weaknesses in the interview conduct for further improvement such as the following reflection about my response in the interview with Debra who cared for her grandmother and her aunt (Figure 19.1.).

Personal reflection; Int14: Debra cared for her grandmother and her aunt.

In some interviews, I started to talk about organization of services and informed FCs how they worked such as in interview 14 with Debra when we were discussing the inability of getting GP prescription from the hospital. I felt I should not have been done that. However, my understanding of CGT allows for co-construction of knowledge between researcher and participants so I felt I should give some clarification to the participant about the services to get clear interpretation.

"Like I said to the palliative care when they came out and the district nurse, why can't you go up to the hospital? And she said because you can't, you can't get prescriptions from the hospital. And I were like you've got a hospital on the doorstep with enough medication that we need, and I just cannot understand how you can't just go to the hospital and get that medication from the pharmacy. But it's because it's a GP prescription" (Int14: Debra cared for her grandmother and her aunt)

"Because (there is different) funding body of each provider of services but in the same time it's the access of the care when you need it, like the GP is under certain collaboration for funding and the hospital is under another one. So this is my understanding, it's different between …" (Int14: Interviewer)

Figure 19.1 Field notes extracts

Field notes also signposted me to areas and topics that needed further exploration in future interviews through the review of the summary points documented. For instance, challenges with work life while providing caregiving was experienced by FCs from the first interview and this was documented as an interesting point in the third interview as it kept arisen in the subsequent three interviews (Figure 19.2.).

Points addressed during the interview; Int 03; Amber cared for her mother Angela with Ovarian cancer.

Amber experienced challenges in keeping at the top of her work rather than her taking care of her mum. (An interesting point is how caring is added burden to working life and what support could be offered either by work or other agencies?)

Figure 19.2. Field notes extracts

Being reflexive about data analysis and interpretation process is a key aspect of qualitative research and establishing trustworthiness about the findings (Engward and Davis, 2015, Korstjens and Moser, 2018). I tried to be detailed about how data were analysed and interpreted to help establish this aspect. However, challenges were experienced in moving from description to a higher-level analytical schema that best theoretically described FCs' experiences. Moving back and forth through the data, writing theoretical memos and regular debriefing with the supervisory team in each phase of analysis helped me to step further with this process until the theory was developed. Furthermore, continuous writing about the relationships between subcategories and diagramming provided clarity on how the developed categories could be related in a meaningful systematic theoretical interpretation. Decisions on which data to include in the findings were considered in the light of the study aim and objectives. I treated all FCs' narratives as equally important and tried to keep their voices in the interpretation; I checked this by comparing data interpretation with FCs' narratives. The interviews were mainly focused on the experiences of EoLC at home; however, there were some narratives related to other settings, such as hospital, palliative care unit and hospice. This created some challenges separating them but through a careful review and scrutiny of the transcripts I was able to exclude non-relevant experiences.

Dealing with preconceptions is considered a data analysis challenge in grounded theory studies (Charmaz, 2014). Therefore, I realised that it was important to consider and identify my preconceptions and be open

to understand what the data told me regardless of my existing ideas about the phenomenon. Various preconceptions were formed during exploration of the literature (DeCarlo, 2018). For instance, I thought that the majority of PwC could die at home with appropriate support to them and their FCs. I did realise that it might not be possible on some occasions where support needs increased. Caring dyads needed to accept changing care decisions while being supported by HCPs. I also found that caregiving experience is not only a stress and burden, but it could also be rewarding if facilitated by formal support. Being reflective about these preconceptions and showing flexibility in changing them with the identified data helped me to learn more about this study population and develop the theoretical interpretations.

The final reflexive point in this study was with regard to the writing process. Engward and Davis (2015) argued that writing a qualitative research report could differ according to the purpose, methodology and audiences. In grounded theory, there is a general interest in representing the social processes occurring in the data in a higher analytical sense rather than being descriptive (Charmaz, 2017). Although an interpretive grounded theory report could be far from FCs' original verbatim narratives, it could still preserve their voices in the representation of the social phenomenon explored (Engward and Davis, 2015). In this study, I found that providing a clear description of the context in which the interview occurred and illustration of the findings with relevant quotes could help making the sense of the findings' interpretations with respect to their related context (Engward and Davis, 2015).

Considering the purpose of this study is an educational requirement for a qualitative PhD research degree I realised the importance of meeting certain quality criteria (Engward and Davis, 2015). I reviewed the methods of reporting qualitative research (Tong et al., 2007) at the planning stage as well as an assessment framework was used to evaluate this study at the end (Appendix 8.). This helped me to plan and report my fieldwork and findings to achieve the required quality.

4.6. Chapter summary

This chapter discussed the methodological approach adopted in this study. It provided justification for the research paradigm used and the chosen methodology. It elaborated on the study context, sampling, and recruitment procedures. The study field work and analysis were reported with detailed discussion of the ethical issues that were encountered. Strategies for establishing study rigour and trustworthiness were mentioned and the chapter concluded with a reflexive statement. The next chapter presents the study findings in the light of the developed theoretical interpretations.

CHAPTER FIVE: FINDINGS

5.1. Chapter introduction

This chapter discusses the findings of the present study which starts with an overview of the participants' recruitment data. This is followed by a description of the characteristics of FCs who participated in this study. There will then be an overview of the theory that was developed from the data. This includes a description of the major theoretical categories representing the essence of the FCs' experiences, accompanied by a detailed explanation of the underpinning processes that led to the inductive formulation of the major theoretical categories.

5.2. Participants recruitment data

26 FCs of PwC participated in this study from 59 eligible participants. Majority of FCs (n=19) were recruited through the contact with HCPs/research staff. Some recruitment challenges were experienced such as non-response (n=22), refusal (n=10) and withdrawal of some participants (n=1). A summary of participants' recruitment data is reported in Table 6.

Table 6. Summary of participants recruitment data

Recruitment strategy/participation status	Eligible	Non-response	Refused	Withdrew	Participated	Refusal/ withdrawal Reasons	Recruitment challenges
Research staff/HCPs	52	22	10	1	19	- Emotional distress. - Refused participation after discussion with family members. - Considered withdrew due to the non-return of written informed consent after several contacts.	- COVID pandemic limited the opportunity to identify/ approaching possible FCs who would have visited the hospice regularly. - Some FCs were identified eligible; however, PwC had reached the active dying phase or died when the planned follow up call was due to take place.
Social media/ NHS trust intranet/ Participant referral	7	0	0	0	7		
Total	59	22	10	1	26		

5.3. Family carers characteristics and context of caregiving and formal support

The present study reports the experiences of 26 FCs who cared for 24 PwC. Most of the PwC were female patients (n=13). Many of them were in the age range (55-75) years old (n=17). The prominent type of cancer was gastrointestinal cancer (n=10) (Table 7.).

Table 7. Family carers and people with cancer characteristics

Int. No	FC	Age	Employment Status	Living in the same household	Relationship to PwC	PwC	Age	Cancer type
01	Elizabeth	(60-65) yrs.	Working	Yes	Sister	Richard	(50-55) yrs.	Throat cancer
02	Barbara	(40-45) yrs.	Working	No	Daughter	Margaret	(60-65) yrs.	Breast cancer
03	Amber	(25-30) yrs.	Working	No	Daughter	Angela	(55-60) yrs.	Ovarian cancer
04	Amy	(30-35) yrs.	Working	No	Daughter	Martha	(60-65) yrs.	Lung cancer
05	Victoria	(65-70) yrs.	Not working	Yes	Wife	Robert	(65-70) yrs.	Oesophageal cancer
06	Sarah	(45-50) yrs.	Working	No	Daughter	Jessica	(65-70) yrs.	Liver cancer
07	Jennifer	(50-55) yrs.	Working/then on leave	Yes	Wife	William	(55-60) yrs.	Oesophageal cancer
08	Emily	(60-65) yrs.	Working/then on leave	Yes, but later on	Daughter	Jean	(70-75) yrs.	Pancreatic cancer
09	Amanda	(35-40) yrs.	Working	No	Daughter	Mark	(65-70) yrs.	Lung cancer
10	Heather	(70-75) yrs.	Not working	Yes	Wife			
11	Maria	(55-60) yrs.	Not working	Yes	Wife	Thomas	(50-55) yrs.	Prostate cancer
12	Natalie	(50-55) yrs.	Work from home in COVID	Yes	Wife	Albert	(45-50) yrs.	Oesophageal cancer
13	Olivia	(60-65) yrs.	Working	Not mentioned	Daughter	Ann	(75-80) yrs.	Lung cancer

Int. No	FC	Age	Employment Status	Living in the same household	Relationship to PwC	PwC	Age	Cancer type
				Yes, but later on	Sister	Rachel	(55-60) yrs.	Breast cancer
14	Debra	(35-40) yrs.	Working	No	Granddaughter	Ann	(75-80) yrs.	Lung cancer
				No	Niece	Rachel	(55-60) yrs.	Breast cancer
15	Laura	(40-45) yrs.	On student leave	Yes, but later on	Daughter	Susan	(70-75) yrs.	Pancreatic cancer
16	Stephanie	(40-45) yrs.	Working/then on leave	Yes	Daughter	Sophia	(60-65) yrs.	Brain cancer
17	Daniel	(40-45) yrs.	Working / Furloughed during COVID	Yes	Husband	Linda	(50-55) yrs.	Pseudomyxoma peritonei
18	Donald	(65-70) yrs.	Not working	Yes	Husband	Christine	(70-75) yrs.	Lung cancer
19	George	(80-85) yrs.	Not working	Yes	Husband	Teresa	(80-85) yrs.	Liver cancer
20	Abigail	(45-50) yrs.	Working	No	Daughter	Jack	(70-75) yrs.	Lung cancer
21	Christina	(60-65)yrs.	Furloughed during COVID/ then left work	Yes	Wife	Matthew	(55-60) yrs.	Renal cancer
22	Marilyn	(70-75)yrs.	Not working	Yes	Wife	Andrew	(70-75) yrs.	Melanoma
23	Withedrew from the study							

Int. No	FC	Age	Employment Status	Living in the same household	Relationship to PwC	PwC	Age	Cancer type
24	Doris	(55-60) yrs.	Not working	No	Daughter	Patricia	(85-90) yrs.	Bowel cancer
25	Carolyn	(60-65)yrs.	Working	No	Sister	Eric	(60-65) yrs.	Renal cancer
26.1	Rose	(60-65) yrs.	Working	No	Close friend	Brian	(60-65) yrs.	Bowel cancer
26.2	Frank	(55-60) yrs.	Not working	No	Close friend			

Family carers in the study were predominantly female (n=22) and more than half of them (n=14) were more than 55 years old. Generally, most of the FCs in the study supported either a spouse (n=10) or a parent (n=10). Primarily the caregiving experiences for most of FCs (n=21) occurred during the Covid pandemic. The duration of caregiving was more than 6 months for many of them (n=10). However, some FCs (n=9) were not able to clearly define the duration of caregiving due to the changing pattern and intensity of caregiving over the whole period of illness. Many FCs (n =17) were working while providing care to PwC. However, 2 FCs were on special work arrangements such as the furlough scheme / working from home during the COVID pandemic, and 4 FCs out of 17 stopped working or took a leave to care towards the end. More than half of the FCs (n =14) lived in the same household with the PwC or stayed with them when they started to deteriorate. The majority of FCs (n =23) were former FCs who were either bereaved or whose caregiving was on hold due to the admission of PwC to an in-patient setting. The duration of bereavement for most of the bereaved FCs (n =15) ranged from 2 months to 12 months. The place of death for the PwC was either home (n =9) or institutional death (hospital n=4, hospice n=5).

Family carers in the study engaged in various caregiving tasks, which included helping with activities of daily living such as feeding, dressing, and personal care. They also provided psychological support and social companionship for PwC. Some FCs delivered medical care such as, simple health checks (e.g., vital signs), and medication administration. However, others performed more complicated medical tasks such as,

colostomy care and wound dressing. It was evident through the interviews that caring dyads received support from a wide range of organisations and professionals. The formal support included professional visits, equipment provision, respite care, out-of-hours support, and emotional and bereavement care.

5.4. Overview of the findings and the developed theory

"Facing the caregiving chaos in the light of formal support … A journey of reward, guilt, and regret"

Caring for PwC at home during EoL was a complex chaotic experience with different dimensions that occurred concurrently without a defined time span during the caregiving journey. In other words, EoL caregiving experiences did not follow a linear stable pattern. However, experiences could change from time to time depending on the nature of the challenges that FCs would face during the caregiving journey, their ways of coping, and the formal support offered and its associated experiences. The interaction between the chaotic caregiving experiences, adaptation to the caregiving chaos, and the FCs' experiences of the formal support resulted in the emergence of feelings of reward or guilt and regret. However, the dominance of any one of these feelings was determined by the interplay between the two interacting processes: living in the chaos of caregiving and interacting with formal support.

Figure 20 illustrates a visual model **"Facing the caregiving chaos in the light of formal support … A journey of reward, guilt, and regret"**. This model was developed based on FCs' iterative shifting

between the different facets of their caregiving experience that was characterised by chaos. This model illustrated that living in the chaos of caregiving was the essence of FCs' experience that involved various facets, such as experiencing the shock of unexpected diagnosis and prognosis and being new to family caregiving. While coping with this chaotic experience, FCs interacted with formal support which formed a nested experience within their chaotic caregiving journey that either increased or reduced the experienced chaos. Feeling rewarded versus guilt and regret was another major experience that was embedded in the chaotic context of caregiving while interacting with formal support. Although, feeling rewarded was a positive dimension of facing the chaos of caregiving journey, it could be intertwined with guilt and regret emotions which illustrated the chaotic nature of emotional experience in EoL cancer caregiving.

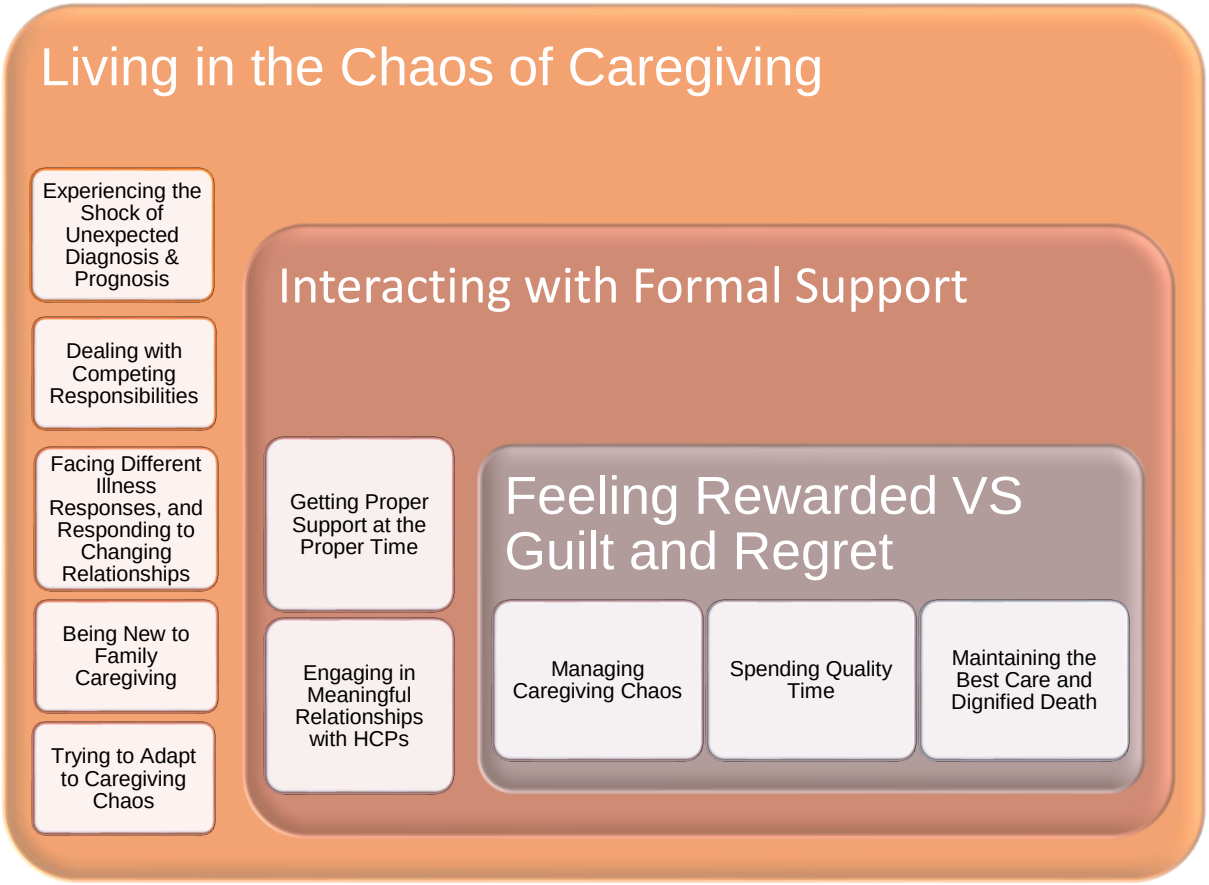


Figure 20. Theoretical model outlining the interaction between caregiving chaos and formal support services experiences

In the current theoretical model, three major categories were presented that resulted from the grounded theory analysis: living in the chaos of caregiving; interacting with formal support; and feeling rewarded versus guilt and regret. The first category reported the experience of dealing with the disturbance caused by cancer caregiving at EoL, which yielded a significant sense of disruption, conflict, and confusion. These feelings were experienced as a result of the properties of this chaotic experience, such as the unexpectedness of diagnosis and prognosis, dealing with competing responsibilities, facing different illness responses, and responding to a changing relationship with PwC, and being new to family caregiving.

However, in response to this disturbance, many FCs tried to cope in their own ways, depending on personal abilities and resources, and used strategies, such as creating a new normal, being resilient and thinking rationally and positively, sharing caregiving with the informal support network available, and developing their skills through self-learning about caregiving. Although they helped FCs to adapt, some of these processes, such as creating a new normal, increased their sense of disruption and confusion.

The second theoretical category depicted the social process of interaction with the formal support system and HCPs. The experiences of these interactions had the potential to help FCs to cope and lessen their sense of confusion and vulnerability and trigger a sense of reassurance. This might be achieved through supportive interactions, which could enable FCs to build a more positive impression of their

caregiving experience. Successful interaction with formal support depended primarily on two essential aspects: getting proper support at the proper time and engaging in meaningful relationships with HCPs. However, if this was not achieved, a heightened level of chaos, confusion, and vulnerability could occur, which consequently affected their overall interpretation of their caregiving experience.

The third theoretical category involves experiencing a sense of reward versus guilt and regret. A sense of reward was experienced when FCs were able to achieve their personal aims of caregiving at home for the PwC, such as managing the caregiving chaos, spending quality time, and maintaining the best care and a dignified death for PwC. However, the feelings of regret and guilt were evident if the caregiving journey did not proceed as planned and expected.

In summary, three interrelated FCs' experiences were identified in the context of EoL cancer caregiving at home. In the following sections, the properties of each will be explored in detail with supportive extracts from participants' narratives.

5.5. Living in the Chaos of caregiving

Chaos is an English term that is used to describe a state of confusion and disruption (Cambridge University Press & Assessment, 2023). In the present study, caring for PwC at EoL was a chaotic experience that was lived by FCs. This disruption was influenced by the unexpectedness of the diagnosis and the associated caregiving commitments, as well as the uncertainty around the prognosis. This

chaotic experience was also intensified if the caring dyad's relationship changed and deteriorated as a result of the illness's physical and psychological impacts on PwC and their response to illness. The impact of the illness could make PwC behave in a way that is not familiar or distressing to FCs. Furthermore, the experience of chaos escalated if FCs had to balance new caregiving commitments with their existing responsibilities. This was especially the case where new commitments involved complex tasks for which FCs felt poorly prepared. In response to these chaotic experiences, FCs tried to adapt in several ways to minimise the level of experienced disruption. In the following sections, the different aspects and contexts of the chaotic caregiving experience were described along with the ways that FCs relied on to cope with their experiences.

5.5.1. Experiencing the shock of unexpected diagnosis and prognosis

Caring for PwC was an almost unexpected event in the lives of FCs in this study. For some participants, the illness started with simple symptoms, such as back pain or earaches that were not expected to indicate cancer. However, in some FCs' situations, it could have been a long time before a cancer diagnosis was confirmed after which it spread and progressed seriously. Maria described the unexpected diagnosis of her husband's prostate cancer after several examinations without any clue of his disease during this time.

" He was not very well and had lots of doctors' appointments and nobody was seeming to be getting anywhere… He was referred to hospital, again he was constantly dismissed. They found it probably two months after, totally by

accident. When it was found it was metastasis, it had spread." (Int11: Maria, cared for her husband)

However, the shift from experiencing minor symptoms of PwC to dealing with unexpected serious illness made FCs experience their first instance of emotional shock and chaos in their journey of caregiving. Stephanie described her emotional shock regarding her mother's diagnosis.

"… it was all a bit of a shock because she was fine and then she was being treated for an inner ear infection, labyrinthitis for three weeks…they kept prescribing different medications, to the point that we thought mum was becoming dehydrated, wasn't getting better. So we sent her to hospital where they thought she may have had a stroke and they scanned her and it became apparent that she had a white mass on her brain." (*Int16: Stephanie cared for her mother)*

This emotional shock increased when FCs received the prognosis of the terminal stage of PwC which diminished their hope and expectation of recovery.

"Upon further investigation, it was the metastasis and it was too progressed, so she couldn't have any treatment, there was no operation… from that then we were told she has weeks to live. So, it was all a very big shock". (Int16: Stephanie cared for her mother)

Family carers struggled to comprehend the swiftness of receiving the diagnosis, navigating the healthcare services, and containing the emotional shock of a terminal prognosis while making the critical decision

of caregiving at home. This was echoed by Emily who was caring for her mother with pancreatic cancer.

"it was a pancreatic cancer and there was nothing could be done and it was just that whole absorption of information and it slightly surreal because it can't really be happening my mother have been plausibly well… then we just on that roller coaster of she has been transferred here (hospital) she has having this test that test the other test radiotherapy to see they could do anything that all that didn't help until in the end it was just like no let just bring her at home." (Int08: Emily cared for her mother)

However, a minority of FCs declared that they felt frustrated about losing the possible opportunities for cancer control and treatment for PwC. In the case of Mark, Heather expressed her frustrations about the delay in diagnosing her husband's cancer and being treated irrelevantly for a deep muscle strain.

"*He went for the x-ray and it was cancer in his lungs, which my husband was obviously upset about and I was because if he'd have gone from the x-rays six months previously when he first went to the doctor, it might not have been as advanced as what it was." (Int10: Heather cared for her husband)*

Some FCs, like Amy, described disease progression as a ***"Roller coaster"*** which was formed of unexpected, varied stages of rapid and slow progression.

"It was an absolute roller-coaster because it started off as basically a little bleb it was millimetres big it were tiny she had the radio therapy and that seem to slow it down so that was the up hell bit of the roller- coaster we started to pick up and then it came back more aggressive…" (Int04: Amy; cared for a mother).

Meanwhile, any unexpected change in prognosis was another source of emotional shock for FCs which increased their sense of disruption. Debra who cared for her aunt described this prognosis transition which brought about this emotional shock.

"… they told us that we'd got five years with her… GP told her that she was now classed as palliative for under 12 months, which came as a bit of a shock to us all. To go from five years to under 12 months." (Int14: Debra cared for her grandmother and her aunt).

Conversely, the sense of chaos was less pronounced if cancer had made steady progress with a long period of survivorship. This allowed for some normalisation and integration of the progressive illness into family life. This was the case with Margaret who received a stage (IV) cancer diagnosis nine years prior to her death. Her daughter, Barbara found that long survivorship and her anticipation of the foreseen outcomes of her mother's illness lessened her distress and anxiety.

"… every time you can't live in a certain level of anxiety because you know … one day you go to the oncology appointment and he/they will say I am sorry there is nothing more I can do we got (to) that point a couple of time(s)… so we would always just live this almost naivety that it wasn't actually gonna happen… because the cancer just been a part of the family and we just we went along with it and you just do it…"(Int02: Barbara cared for a mother).

The unpredictability of prognosis and associated health problems left FCs uncertain about the new challenges in each day of their experience. Stephanie was asked to describe a daily routine for her

mother's care. She expressed her difficulty in knowing what she would face each day.

"She (her mother Sophia) literally deteriorated each day… every day was different, it had new challenges…" (Int16: Stephanie; cared for her mother).

This state of uncertainty surrounding the prognosis and prospective challenges left FCs in a constant worrying state. This was experienced by Elizabeth who was providing care to her brother.

"… to be perfectly honest with you I do not know what is ahead of us…" (Int01: Elizabeth; cared for her brother).

In some circumstances, this uncertainty made it difficult for FCs to predict and arrange the support package for PwC at home. For Olivia, the unexpectedly rapid deterioration of her sister's condition made her feel rushed and distressed while she was trying to arrange support.

"If we would have known for definite three months before, then we could have put things into place., instead of scrambling for things… We had no inkling up until that day that this was happening because she had been fit and well." (Int13: Olivia; cared for a mother and a sister)

Another consequence of this state of prognostic uncertainty was the difficulty experienced by FCs when considering potential decisions and actions regarding the support of PwC. For instance, Elizabeth experienced an emotional dilemma and conflict between her need to take leave from work to rest and focus only on her brother's care and the need to ensure that she took this leave at the optimum time.

"… I am thinking should I trying get some time off but if I have taken my time off too early and then I have not get no time later when things getting really bad and it is right They can't tell me how long… and I don't want to do nothing wrong and I don't want to lose time…" (Int01: Elizabeth; cared for a brother).

In summary, the unexpectedness of diagnosis and prognosis and the rapid deterioration placed most of FCs in this study in a confused state. This formed a part of the chaotic caregiving journey, which influenced their ability to make care-related decisions and their feeling of doing their best to support PwC.

5.5.2 Dealing with competing responsibilities

Caring for PwC in the family was not usually the only responsibility held by FCs in this study. They tended to have other multiple responsibilities, such as family and work, as well as their own well-being. If these commitments overlapped, this created a further complexity in the chaos of EoL cancer caregiving. For instance, Amy described her significant difficulty and distress while caring for her mother, continuing to work and caring for her children. This made her feel trapped in a closed cycle of commitments without any opportunity for even socialising.

"… it was very very very hard a lot of people got neglected trying to juggle… my kids, work and mum. (It) was horrendous to be honest." (Int04: Amy; cared for a mother).

Managing caregiving became more difficult, and stress increased when FCs combined the support of another family member with their caring commitments for PwC. For instance, alongside caring for her

husband, Victoria was supporting her son, who was suffering from night-time seizures.

"My son… had night-time seizures… he is under control but he always got that worry during the night so I have got that care really." (Int05: Victoria; cared for a husband).

Other aspects of competing responsibilities involved a situation where FCs suffered from health problems themselves and needed support, which increased their struggle and distress. Doris had fibromyalgia and a spinal cyst causing mobility problems, which placed restrictions on her ability to help with the physical caregiving tasks for her mother. She experienced great difficulty maintaining an equilibrium between caring for her mother and maintaining her own well-being.

"…it's been difficult really balancing caring for mum, caring for myself and supporting her through her illness." (Int24: Doris; cared for a mother).

Meanwhile, maintaining work commitments while caring for PwC was another challenging issue for several FCs in the study. This resulted in exhaustion and physical tiredness when combining both, and possible feelings of guilt due to potential role insufficiency, which was reported by Amber, who was working as full-time teacher while caring for her mother.

"I think the main challenge was just being physically tired and not being able to put as much in my job because I am so tired from taking care from my going back and forwards from home to work to mum's house…" (Int03: Amber; cared for a mother)

However, other FCs found that being involved in other commitments, such as work, enabled them to maintain normality, which would lessen the experienced chaos of caregiving. Jennifer continued to work until the last two months of her husband's life.

"I was able to keep working and that was good for everybody, I wanted to keep some sense of normality within the family. I think that's important. So work allowed that to happen." (Int07: Jennifer, cared for a husband).

It was evident that workplace support, such as flexible working arrangements, was essential for FCs to balance their multiple commitments. Several working FCs reported that their employers' support lessened the conflict that could have been experienced between work and caregiving commitments. Amber echoed this when she described her employer's flexibility and acknowledgement of her caregiving responsibilities, which made her feel more fortunate.

"My work was very supportive in terms of like if I needed to leave or If I needed to be with mum this morning she was in the hospital they would know about it and they would be more than lenient in terms of work…" (Int03: Amber cared for her mother)

However, this was not the case with some FCs. Elizabeth usually found it a struggle to get some time off work to care for her brother and attributed that to her manager's lack of acknowledgement and understanding of her caregiving responsibility and the difficulties she had.

"I would like time off and there was no cover and I do not think my boss is brilliant (or) *understands me about it… I get quite annoyed…" (Int01: Elizabeth; cared for a brother).*

Issues related to the pandemic made juggling work and caregiving easier for some FCs. They described how the pandemic work arrangements, such as home working, and the furlough scheme enabled them to dedicate time to caring for PwC. For instance, Daniel, who worked fulltime, reported how COVID work regulations facilitated caring for his wife.

"… I do have a full-time job, which I suppose in a way Covid was very fortunate for us on that one… it's been good for us for work-wise because I've been furloughed and then semi-furloughed for just over a year now." (Int17: Daniel; cared for a wife)

On the other hand, the COVID pandemic made it difficult and more frustrating for some FCs who were working as HCPs. They faced the dilemma of either choosing to care for PwC or continue to work in the face of the national crisis. Debra talked about her experience when she refused to be redeployed and continued to work during the pandemic while feeling guilty about not being able to contribute more to her aunt's care.

"I could have quite easily have asked for redeployment and whatever but it's not in my nature to run away whether it's a pandemic or not, if somebody needs caring for then that's what I'm there to do. So I was quite torn to start with that I'd looked after everybody else and not looked after her (her aunt Rachel)." (Int14: Debra cared for her grandmother and her aunt)

In summary, dealing with multiple commitments while caring for PwC at home added another layer of complexity to the chaotic caregiving experience. This was a consequence of FCs' endeavours to maintain a balance between caring and other commitments, which was not always feasible in many instances and led to physical and psychological suffering.

5.5.3. Facing different illness responses, and responding to changing relationships

The response of PwC to illness and the impact of this on their relationships with FCs was another aspect of the chaotic caregiving experience. It was apparent that the combination of the illness and their increased need for help and care affected the relationship between PwC and FC. In some instances, strained relationships appeared in the form of limited interaction between PwC and FCs, which frustrated FCs and made them feel unappreciated. For instance, Mark stopped talking to his wife Heather at all. However, he was still communicating with his visiting paid carers.

"He just completely blocked me and he wouldn't talk to me… And yet when the carers came, he would talk to them, laugh and joke with them while he was able. And that hurt me that he couldn't speak to me. And I was the one that was with him 24 hours a day and I'd sit at the side of his bed for hours and he wouldn't say anything." (Int10: Heather, cared for her husband)

However, the nurse specialist explained to Heather that her husband's changed interaction pattern was related to his upset about his condition and his increased need for support, which had an impact on his sense of pride.

"… she (nurse specialist) just said I believe he's very bitter about what's happened to him and his pride is such he doesn't want or doesn't like you actually seeing him like this and going through it… that's the only thing I can relate to that she said…" (Int10: Heather, cared for her husband)

Another form of strained relationships appeared in displaying anger toward FCs, which was perceived as a projection of anger feelings related to the illness, as explained by Christina, who was caring for her husband Matthew.

"He would swear at me and things like that. He's never swore at me in my life but I just put it down to that it was the pain. So as somebody looking after somebody with cancer, that side of it's very hard. It's like you've got another person in the house." (Int21: Christina, cared for her husband)

On the other hand, some FCs talked about the positive response of the PwC to their illness and its impact in enhancing FCs' coping with the chaotic caregiving experience. In her narratives, Doris talked about her mother's resilience towards illness, which lessened her distress.

"She's (Her mother Patricia) very positive and very independent and she's always sort of… after her surgery she's like right, that's it, onwards and upwards now. And if it comes back it comes back and that's how she's handled it. And I'm lucky, I'm grateful for that really, otherwise I think it would have been too much pressure for me to give her all the support she needs." (Int24: Doris, cared for her mother)

Similarly, if a trusting caregiving relationship existed between PwC and FCs, this helped in achieving a peaceful stay at home for PwC, facilitated the management of caregiving chaos and increased

recognition of this as an achievement. This was evident in Natalie's discussion with her husband regarding the prospective caregiving situation.

"The last conversation we had when he came home, I said to him 'Do you trust me?' and he said 'Yes' and he looked me in the eye with tears and I said 'Well that's okay because I'll be with you to the end and you're not going anywhere'. And that's what I did. And that's what he wanted." (Int12: Natalie cared for her husband)

To conclude, PwC's response to their illness and their relationship with FCs constituted a segment of the chaotic caregiving experience. If negative responses to illness and a strained relationship with PwC were the case, it would lead to further FCs' upset and frustration. However, if positive reactions towards illness were displayed by PwC and trustful relationships existed, it would facilitate FCs' dealing with caregiving.

5.5.4. Being new to family caregiving

Adopting the new role of caregiving created an increased sense of disturbance in life and anxiety, especially if the person felt that they were lacking the necessary preparation for this role. On many occasions, caregiving involved undertaking complex tasks that required clinical knowledge. This included manual handling, dealing with a colostomy, wound dressing, monitoring, and responding to emerging complaints, and symptom management. Most of FCs experienced caregiving for the first time in their lives. This created a great sense of apprehension and confusion due to unfamiliarity with these tasks. Elizabeth echoed this when she talked about caring for her brother.

" It is worrying because obviously (I've) never done these things." (Int01: Elizabeth cared for her brother)

Similarly, Amy talked about her feeling of unpreparedness for caring for her mother, since she did not have the necessary qualifications or knowledge for caregiving.

"It is something that I have not experienced before… when it is your own mum and we did not have any qualifications or any know how to do it…" (Int04: Amy, cared for her mother)

For some, the sense of not being qualified and prepared for caregiving triggered a sense of fear and uncertainty about stepping into this role. Some FCs deliberately appeared unable to manage due to their concerns that they would be deprived of the necessary support they should be entitled to if they appeared to be managing caregiving responsibilities. Laura talked about how she tried to make her struggle more explicit so that she wouldn't be deprived of the available support for her mother.

"Certainly, initially I was very conscious of not adopting the role of carer because I didn't feel kind of qualified to do it. I mean obviously of course I would, I was her daughter and that's what I would do but it was being conscious of the fact that if I told them that I'd move in, I would care for her, that she wouldn't then get the help and assistance that she was entitled to but also might be available." (Int15: Laura cared for her mother)

The perception of not being prepared for caregiving increased with the unexpected complexity of certain tasks; this had a cascade effect on the emotional burden FCs experienced. In other words, caregiving for

PwC at EoL could include complex tasks that required specialized skills and knowledge. When FCs realised their insufficiency regarding the practical and emotional preparation for these tasks, this heightened their sense of confusion and distress. For instance, Robert suffered from oesophageal cancer and needed colostomy care. However, his wife, Victoria experienced great difficulty in dealing with this and related complications, which became more difficult with cancer progression, making her feel overwhelmed.

"… I did found the stoma hard I am understanding the stoma bag (but) I found it very difficult to do (it) to refit the all the rest of it because he keeps leaking…" (Int05: Victoria, cared for her husband)

Meanwhile, emotional insufficiency to deal with these complex tasks seemed to be a contributing factor to FCs' feelings of burden and struggle. In another case, Andrew had melanoma and required several wound dressings, which were done completely in the initial period by his wife, Marilyn. However, the magnitude of this procedure was not expected, and consequently, Marilyn experienced significant emotional trauma.

"I don't know how I did it (wound dressing) to be honest…and I did it for a long, long time ... But no, I'd no idea that I'd be doing something like that, it was just beyond me. And to be honest beyond anyone." (Int22: Marilyn, cared for her husband)

One of the most reported challenges that FCs faced in their new experience of caregiving was cancer pain management. This placed FCs under perpetual distress and worry about keeping PwC comfortable and

experiencing less pain. Christina cared for her husband with renal cancer, and she considered managing pain to be the most challenging task ever.

"If I think back now it was mainly the pain that was the problem all the time. Trying to keep on top of the pain." (Int21: Christina, cared for her husband)

The complexity of pain management appeared in the dilemma of maintaining effective pain control without causing serious adverse effects. This was experienced by Laura, whose mother who had pancreatic cancer, suffered from various side effects, such as severe constipation.

"I think it was trying to get the balance of the medication that she needed to control the pain. She had a lot of problems in terms of the side effects from the medication." (Int15: Laura, cared for her mother)

Family caregiving increased in complexity when it involved challenging instrumental tasks that needed particular skills, such as moving and handling. This was commonly experienced when cancer progressed and affected the mobility of PwC, with an increased need for support in personal care. This was a challenging task for Stephanie, who cared for her mother with brain cancer who needed help with personal care.

"And of course then there's moving mum onto the commode because she was very dizzy with it being on her brain, very sick. So I had to move her onto the commode myself one day and she fell. And I didn't know what to do, how to do it." (Int16: *Stephanie cared for her mother)*

Similarly, Amy considered this significantly challenging for her when her mother Martha became bedbound.

"Toward the end we did it (wash her mother and changing) and that was one of the hardest things that I think to go through with actually trying to care for her move her wash her." (Int04: Amy, Cared for her mother)

Therefore, FCs' preparation was perceived as necessary for dealing with tasks that required technical knowledge. However, if preparation was lacking, it increased the confusion and struggle that FCs experienced. For instance, Amy felt worried and unsafe while she was moving her mother, as she lacked the necessary preparation that would have built her confidence.

"… I would say that would been nice if it was offered is extra like points on how to keep her clean…. when she started getting in bed… not known how to wash her and change her properly that was it honestly feel like you was gonna break her if you try to move her." (Int04: Amy, Cared for her mother)

However, the uncertainty and rapidity of prognosis increased the need for proactive and swift preparation and guidance, which was highly recommended by FCs like Olivia, who described this as a ***"Crash course"*** in patient care for getting ready promptly for caregiving.

"… it's sort of like giving them (the families) a crash course in how to care for a patient, it's giving a layman, somebody who's never worked in care or never worked in the hospital or anything like that, giving them a crash course in… this is the best way of moving them up the bed. If you're going to change the bed, this is the best way of doing it to cause them the least amount of discomfort." (Int13: Olivia, cared for her mother and her sister)

On the other hand, some FCs in the study were either professionally or personally prepared for their caregiving journey. In some instances, this preparation was built through their previous working experience as HCPs. For example, Jennifer was a nurse and stated that this enabled her to deal with her husband's medication at home.

"I managed his medication that was given… I suppose I'm a nurse aren't I, so I know what I'm doing with medication. I was able to support with that." (Int07: Jennifer, cared for her husband)

Similarly, having this professional knowledge and skills enabled some FCs to prepare and empower other family members who shared the caregiving with them. This family member's preparation was in the form of informal training and advice to help them deal with caregiving tasks. A typical example was Debra's caregiving situation, she was working as a healthcare assistant, and used her skills and knowledge to prepare her other family members for the caregiving of her grandmother.

"*So when we brought my nan home, I literally got all… luckily my mum's one of nine,… and there's six girls, so I literally got all the girls… Gave them a little bit of a moving and handling lesson." (Int14: Debra, cared for her grandmother and her aunt)*

On some occasions, the professional experience of FCs who worked in the healthcare profession had a positive impact on minimising the perceived caregiving burden. Sarah was a healthcare assistant, and when she was asked about the impact of caregiving on her, she minimised any experience of burden. Sarah attributed that to her nature

of work and that she was accommodated to these kinds of caregiving tasks.

"It (Caregiving) hasn't because I was at that time I worked as health care assistant any way so it rarely affect me…" (Int06: Sarah, cared for her mother)

There were other FCs who had experienced caregiving through a previous episode of caring for another member of the family. Therefore, they got used to the ethos of this role and were able to cope with the associated tasks. In this context, Olivia had cared for her mother for five years before her caregiving for her sister started, which prepared her for this role.

"We were lucky enough we knew what we had to do with Rachel (her sister) when it came to the end because we'd already done it with my mum." (Int13: Olivia, cared for her mother and her sister)

To sum up, experiencing caregiving for the first time triggered a sense of confusion and worry due to feelings of unpreparedness and insufficiency. However, if proper preparation was granted, either through working as HCPs or previous personal caregiving experience, FCs' confidence, and their ability to cope with caregiving increased.

It was evident that caregiving in the present study involved various aspects that made this experience more chaotic for some FCs than others. These chaotic experiences resulted from the uncertain experience of diagnosis and prognosis, competing multiple tasks, facing different illness responses, and changing relationships with PwC, and being naive in a caregiving role.

5.5.5. Trying to adapt to caregiving chaos

Family carers in the study responded in various ways to the experiences of chaos and disruption, which started with knowing the diagnosis, prognostic uncertainty, differing PwC's response to illness, and changing relationships and adopting the new role of caregiving. The main goal of their adaptive actions was to get control over the changing circumstances and improve their management of caregiving tasks and demands.

Family carers' personal traits, such as confidence and assertiveness were crucial aspects of their ability to cope. For instance, Stephanie mentioned that her assertiveness, critical thinking, and advocacy skills enabled her to best manage her mother's care at home.

"I'm quite clued-up… I would challenge if something didn't seem right to me, I would challenge it and think that's not right. And mum was in good hands and I did do my best." (Int16: Stephanie, cared for her mother)

This sense of confidence was also echoed in Natalie's reflection about her caregiving journey.

"Was I scared? Damned right I was scared. Did I ever doubt I could do it? No…" (Int12: Natalie, cared for her husband)

These personal qualities contributed to FCs' ability to navigate and cope with the disruption caused by the caregiving journey. Four coping strategies were used by FCs to deal with the chaotic caregiving experience, which included creating a new normal, being resilient, thinking rationally and positively, sharing the caregiving, and learning about caregiving.

5.5.5.a. Creating a new normal

Coping with the new caregiving role usually involved a conflict between the FCs' desire to maintain the normal life routine and the obligations of PwC disease and caregiving commitments. FCs in the study dealt with this conflict in different ways. Some tried to carry on as normal; however, this was dependent on PwC condition. For instance, Jennifer tried to manage illness commitments alongside other aspects of life such as going in holidays.

"We went on holiday to Cornwall and came back for the chemo and went back again, things like that. So we kept going and kept it absolutely full, that was our way of coping." (Int07: Jennifer, cared for her husband)

Family carers used this as a way to maintain normality and lessen the chaos induced by dealing with terminal illness uncertainties. This was echoed in Donald's following narratives about dealing with his wife's illness.

"No, I can't think about it or worry about it every day, every minute of every day because otherwise I'll end up in care. I want to live our life as naturally and as we have done for all these years and enjoy… but just don't sit in the chair staring at a wall worrying about something I've got very little control over..." (Int18: Donald cared for a wife)

However, other FCs dealt with caregiving as an added responsibility that they had to consider and integrate into their life routines and priorities. This consequently increased their perceived burden and the juggling between their commitments. In this context, Amy was a working mother with two children, and when her mother needed

care and support, she felt that another commitment was added to her list of priorities, besides the existing responsibilities.

"I have two kids and it was she became kind of just someone else that I had to (consider) that was one of my priorities." (Int04: Amy cared for her mother)

Such integration involved more effort to cope with these competing responsibilities, which consequently increased feelings of disruption. On the other hand, many FCs in the study dealt with PwC and caregiving as a priority and placed any other aspects of their lives on hold; prognostic uncertainty appeared to be a significant influencing factor in doing this. Laura was doing her PhD in another city when she learned about her mother's illness and the uncertainty surrounding her prognosis, her ultimate decision was to interrupt her study and dedicate time to care for her mother.

"We were kind of given a prognosis, an idea of it could be three months, it could be six months. And I think my attitude was to kind of put mum first as a priority and deal with anything else afterwards." (Int15, Laura, cared for her mother)

It was assumed that caregiving was perceived as a temporary event which allowed some FCs to step out from other roles to care for PwC. In her interview, Stephanie mentioned that she stepped out of her parental role during caregiving while her husband took on this role when she was caring for her mother.

"My children lost me for eight weeks really because I couldn't do it, I couldn't be a mum and so my husband very much took that role and all sorts of roles really… I thought well my children can have me and I told my mum this, I says

the boys have got me forever and I said you haven't…" (Int16: Stephanie, cared for her mother)

Furthermore, re-prioritising was not exclusive to FCs' external commitments, such as work or familial roles. It also involved their own routine and well-being, such as rest, sleep, and nutrition which is arranged around PwC's routines as described by Laura in her following narratives.

"Literally my routine in terms of sleep, meal-times, all coincided with when mum slept or decided she wanted to eat." (Int15, Laura, cared for her mother)

In summary, creating a new normal varied according to PwC's condition and needs. It involved continuing life as normal and keeping other roles' identities. Then, it would change when PwC deteriorated and FCs gave up some of their other roles, which led to further disruption in their lives. Hence, creating a new normal and reprioritising commitments would not resolve the chaos when roles conflict was perceived and guilt feeling regarding role insufficiency was triggered.

5.5.5.b. Being resilient and thinking rationally and positively

Dealing with the chaos of disease deterioration and conflicting roles and commitments would create upset and frustration. However, being resilient and thinking in a positive, constructive way helped FCs cope. For instance, reasonable optimism was a resilient way of coping with the sense of uncertainty associated with a progressive terminal illness. This positive thinking was apparent in Stephanie's situation when she realised the necessity of leaving pessimistic thoughts about her

mother's illness and prospective death and trying to focus on optimistic ideas instead to be able to cope with caregiving.

"… I think it was because I had to stop thinking she was going to die and I had to think she was going to get better to be able to do what I did. I couldn't have done it otherwise. So I was grieving for the first three or four weeks and then I realised I need to stop grieving at this point because I'm going to grieve anyway, I just need to crack on and get through this." (Int16: Stephanie; cared for a mother)

Another example of positive thinking and resilience appeared in FCs dealing with illness complications and deterioration by viewing them as a connection from one stage to another rather than a crisis. This lessened the emotional effects associated with these deteriorations and helped them continue their caregiving journey. Christina echoed this when she was talking about handling her husband deterioration and associated challenges.

"If it's a situation in his illness or it's part of his illness, it's another change, so me saying it's a small bump in the road… what we do is we now change because his condition's changing or another stage or something's happened, so we've stopped for a minute, thought it through and we're going forward again…" (Int21: Christina, cared for her husband)

Similarly, when discussing the challenges that Barbara faced while caring for her mother, Barbara mentioned that she did not deal with them as barriers but dealt with them as a component of the journey which she had to deal with.

“To me what other people may deem to be a challenge I just deem to be is a part of it this what we did this how we dealt with it.” (Int02: Barbara, cared for her mother)

Rational thinking was another way to deal with conflicting demands and caregiving dilemmas in a way that enhanced FCs’ coping. Stephanie was a mother of two young children while caring for her mother during the COVID pandemic. One of the measures that were used to enable key workers to continue working during the pandemic was allowing their children to attend school. Stephanie identified the potential coping difficulties with her mother’s caregiving along with her children’s care if she kept them at home. However, she was aware of the potential risks of transmitting the infection to them, which put her mother at a greater risk. Therefore, Stephanie acknowledged the two conflicting alternatives and rationally chose the option that would facilitate her coping with her mother’s caregiving at home.

“ In the fact that our children had to go to school, we’re keyworkers anyway but we had to make a decision on risk, based on risk. So we thought we couldn’t cope at home with the children here doing what we were doing because both me and my husband hit the ground running all the time, the two of us. On the other side if we sent the children to school and they come back and that spread to my mum… So in the end we weighed up the risk and they went to school… If it wasn’t for them going to school and us being keyworkers, gosh I don’t know… we probably couldn’t have done it and mum would have had to have gone into a hospice.” (Int16: Stephanie, cared for her mother)

Caring for one's own well-being was another form of the resilient and positive attitudes adopted by FCs to mitigate caregiving-related distress. Throughout interviews, FCs talked about their engagement in activities, such as exercising, reading, and socialising with family and friends. These activities provided them with respite and facilitated their coping. Jennifer used to exercise and socialise with family and friends, which enabled her to cope.

"I think I'm a pretty resilient person and I coped, I went to the gym, I did my classes at the gym and that helped. I've got good family and friends who I talked to." (Int07: Jennifer, cared for her husband)

To sum up, resilience and positivity toward illness deterioration and the caregiving demands were another way of FCs' adaptation to lessen their sense of chaos and disturbance.

5.5.5.c. Sharing the caregiving

Having a supportive network of family and friends facilitated coping with caregiving and allowed for maintaining a balance between multiple competing responsibilities. This, in turn lessened the burden felt and allowed quality time to be spent with PwC. This made some FCs in the study feel fortunate to have the support. This was apparent in Olivia's situation, who dealt with caregiving as a teamwork.

"We were lucky that we had got a support there for ourselves, where we could support ourselves. If one of us needed to go running off for medication or go and sort something out, there was still enough of us there that could look after my mum..." (Int13: Olivia cared for her mother and her sister)

Informal support from family and friends appeared in various forms in the study. For instance, it involved intermittent help with caregiving tasks that allowed a respite for FCs. Although Doris was the primary FC for her mother, her daughter used to help with medical consultation visits for her grandmother.

"I've got a daughter and a son, they're both very supportive… I do have more support from her now. She also helps me care for mum, take her to appointments and things like that." (Int24: Doris cared for her mother)

However, informal support not only involved functional tasks but also included supporting FCs emotionally. This had a positive impact on their emotional well-being and gave them a sense of not being alone, which was echoed in Jennifer's narratives about her sister.

"I think my sister more emotionally lifted me…" (Int07: Jennifer cared for her husband)

Sharing caregiving helped some FCs to deal with other competing commitments, such as work. This helped FCs like Elizabeth continue working while providing care for her brother.

"My older sister coming to help so I can go to work." (Int01: Elizabeth, cared for her brother)

On some occasions, it seemed that there was an implicit agreement and acknowledgement of the dual responsibility towards caregiving of PwC. Therefore, FCs found the opportunity to enjoy a break and respite, knowing that others would take over their role. This was expressed by Amy in her narratives.

“I was doing in the week and then my sister used to come over in the weekends while I had a break.” (Int04: Amy cared for her mother)

Similarly, Natalie got a chance for emotional release through daily walking. This was facilitated through support of her adult children who accompanied their father while she was away.

“I’m very fortunate in that it’s a beautiful walk… like the children would be here. So I could go knowing that they were here.” (Int12: Natalie, cared for her husband)

Another form of sharing the caregiving appeared in the equal distribution of activities in an organised system of duties. For instance, Debra talked about the development of a caregiving duties rota so that they shared the responsibilities evenly. This allowed them to share the care, which minimised their sense of juggling and reduced the sense of chaos.

“ We had rotas and things like that and somebody’s always cooking, making sure that we’re all fed, somebody’s on washing machine duties…” (Int14: Debra, cared for her grandmother and her aunt)

This also enabled Debra’s family to enjoy quality time with her grandmother and her aunt.

“And also get that time where when you’re in that room you’re not thinking has the washer finished or is there something to eat, are the tablets done. When you’re actually sat with your mum, your nan or your auntie, it’s quality time because you know that the people outside of the room are keeping busy and doing what they’re supposed to be doing.” (int14: Debra, cared for her grandmother and her aunt)

The feeling of being accompanied and supported by other family members in caregiving process lessened the sense of isolation and loneliness. This was echoed in Natalie's experience with her husband's caregiving.

"… although I was a primary carer, I wasn't on my own, I had… it was all shared with them (her adult children) and they got to know the medical team as well. So I didn't feel alone." (Int12: Natalie, cared for her husband)

However, the COVID pandemic deprived some FCs of this opportunity for informal support while caring for PwC. The restrictions that were placed on social gatherings limited the opportunity for some FCs to have family and friend visits and support. For instance, Stephanie reflected on her upset of not having proper informal support due to the COVID restrictions which would have given her a respite and enabled her to spend more quality time with her mother rather than being overwhelmed with caregiving.

"If it wasn't for Covid, my cousins would have maybe had the children a bit more. I guess it would have because more people could have come and it would have helped me to sit and just talk to me sometimes while somebody was with mum and it would have given me a break. Because I felt guilty being downstairs and not being with her when she was awake." (Int16: Stephanie, cared for her mother)

Similarly, Marilyn felt disappointed about missing the emotional support that she could have had through friends' visits, which were limited by the COVID pandemic restrictions.

"… all of the friends, none of them could come into support, it was only on the phone. Where it would have been nice to have had a hug and company and whatever." (Int22: Marilyn, cared for her husband)

However, apart from the COVID pandemic, in one caregiving situation, a significant sense of frustration and unfairness was experienced by a FC who had limited informal support from other family members who were perceived not to offer the level of support that they should. Although Doris acknowledged that she received some support from her adult children and husband for her mother's care, she was upset about her sister's limited help.

"I've got my sister as well, my other sister but I haven't mentioned her much but mainly because it sounds awful but she doesn't really do anything… I don't get support from her and mum doesn't get support from her really as much as what we should…" (Int24: Doris, cared for her mother)

The sense of unfairness that Doris felt was because of her unfulfilled expectations of receiving more support from her sister.

"And it is quite upsetting, it does cause me quite a bit of distress. And that's just something else that sort of impacts on me because of having to care for mum really. And not getting support from another family member." (Int24: Doris, cared for her mother)

In summary, sharing the caregiving journey was another facet of FCs' approach to managing the chaotic caregiving experience. However, if FCs' expectations of informal support were not met for any reason, this would increase their sense of juggling and their experiences of distress and chaos.

5.5.5.d. Learning about caregiving

Many FCs viewed caregiving as a continuous learning process that was self-initiated and based on experimentation. Maria expressed this opinion in her narratives about her caregiving experience with her husband.

"… you just get on with it and you learn as you go…You make mistakes but that's part of life and part of learning." (Int11: Maria, cared for her husband)

Other FCs thought that engaging in a preparatory learning activity would help them cope with the situation and develop a sense of control over the unfamiliar circumstances. For instance, Laura ordered some pancreatic cancer publications to be prepared for caring for her mother.

"I think me personally I like to be prepared and I like information and I want to find out." (Int15: Laura, cared for her mother)

However, Natalie's initial desire to learn and know more about her husband's disease was a part of her search for hope and optimism.

"I read all the medical papers I could find. I read the research papers published of the oncologist, I read everything I could find. I guess you do that because you're looking for hope really." (Int12: Natalie, cared for her husband)

This caregiving learning process did not progress gradually and required expedited initiatives to adapt to the rapid deterioration of PwC. This was reported in Natalie's description of her caregiving situation.

"A steep learning curve and a very quick learning curve." (Int12: Natalie, cared for her husband)

By contrast, other FCs such as Stephanie found that it was quite challenging to deal with their unpreparedness through self-learning about caregiving skills. This was due to time pressures, which limited the chance for this to happen.

"… initially we didn't have time to go and read bits and do things like that because we hit the ground running." (Int16: Stephanie, cared for her mother)

Furthermore, Stephanie highlighted that a significant gap existed between self-learning through watching video tutorials versus learning by doing through HCPs' instruction.

"That information as I say is on YouTube, you can watch videos and look at things… But that is not the same as getting practical hands-on and doing it. You can't just watch a YouTube video how to move a palliative patient and how to put a nappy on and then just go and do it and be perfect at it." (Int16: Stephanie, cared for her mother)

To sum up, dealing with caregiving as a learning process and trying to acquire caregiving knowledge was a coping response to the unpreparedness feeling and distress. However, it would not be feasible in the context of rapid deterioration at EoL and the complexities of some caregiving tasks that needed specialist advice and training.

In this study, adapting to the chaos of caregiving for PwC at EoL was facilitated by FCs' creativity and positivity. This appeared in their ability to amend their normal routines and adapt their thought process in a positive way. However, the availability of certain external contexts such as informal support networks was a determinant of FCs ability to cope

with the sense of disruption associated with caregiving. Acquiring caregiving knowledge was a solution for some FCs to overcome their apprehension of not being prepared for this new role in their lives.

5.6. Interacting with formal support

It has been seen that FCs experienced a sense of chaos and disturbance after receiving the cancer diagnosis and started to deal with the impacts of the disease and associated caregiving commitments on their lives. Initially, many FCs depended on their abilities and own ways of coping to deal with this chaotic experience. However, the study interviews highlighted that formal support was perceived as a significant empowering resource for FCs and could act as a buffer against the experienced caregiving chaos. Therefore, the FCs' experiences of formal support were interpreted as their experiences of reassurance versus confusion and vulnerability. The determinant of this emotional experience was mandated by two aspects of FCs' interaction with formal support which, involved getting proper support at the proper time and experiencing meaningful relationships with HCPs.

5.6.1. Getting proper support at the proper time

Family carers' experiences of getting the proper support at the proper time varied among the participants in the study. However, it was apparent that they mostly engaged in an intensive process of self-navigation and chasing support. The experience of FCs' getting proper support at the proper time was determined by three aspects, which included: receiving individualised support, ease of access to support and timeliness of support. If FCs experienced facilitated access to

individualised support according to the caring dyad's needs with a timely support response, this gave them a sense of reassurance and helped them cope. If this did not happen, the experiences of chaos, confusion, and vulnerability would be exacerbated.

5.6.1.a. Receiving individualised support

The notion of individualised support in the present study involved two main features: the adequacy of support to meet the caring dyad's needs and the personalisation of support to match the caring dyad's preferences and context. For some FCs, the support offered was inadequate to meet the needs of the caring dyad. While discussing the support experience with Amanda and Heather who cared for Mark, Amanda noted that the received support was not adequate for her father care in terms of number and duration of visits. She identified that her father needed around-the-clock support rather than sporadic care visits for limited time.

"I am sure that how I have got in my head that once you was at home with a care plan person would be in your house 24/7 caring for your father but may be that was the dream rather than the reality of what can be offered but definitely I think more than four 20 minutes visits." (Int09: Amanda; cared for her father)

Therefore, the lack of individualised support that failed to meet the needs of the PwC made FCs feel helpless, lonely, and vulnerable in their caregiving journey. This was confirmed in Heather's interview. Although her husband Mark received the maximum number of care visits, Heather needed more support visits to help with the increased care demands.

However, the lack of individualised support triggered her feeling of difficult coping and frustration.

"So, I was on my own with him, apart from the carers four times a day. But they'd come in and sometimes they'd only be here five or ten minutes and then I'm on my own again. And sort of 18 hours a day constant day after day after day, I was at breaking point. And I couldn't cope no longer." (Int10: Heather cared for her husband)

By contrast, another FC Maria found that the care visits were in excess of her husband care needs which made her declined some support visits.

"What happened is we had four care visits a day and it was too much…We asked for the carers to drop off a few visits because in the beginning that was okay, I could actually manage…" (Int11: Maria cared for her husband)

Another aspect of the **"Individualised support"** construct in the study was the consideration of the caring dyad's routines and preferences for care. For some FCs, the support package arranged ignored PwC's routines regarding the sleep-awaking, meals, and personal care times. Disregarding care preferences and individual routines increased the sense of disruption and support dissatisfaction. In Mark's situation, the care visits were happening haphazardly and were not adapted to Mark's daily routines.

"My expectation I think would be to have discussed with my mum a routine first of all and find out what you normal have… What time does you normally get up and then… then you got some sort of plan in place that to me would seem a logic way to do it and then put the caring around that around the patients needs.

But again unfortunately they would visit when may have the time not when it was sufficient to my mum." (Int09: Amanda cared for her father)

This was also experienced by George while he was caring for his wife Teresa at home.

"We asked for a nurse before half past 8 in a morning because I'm an early riser, the wife was an early riser, we always have been. And the first morning she didn't turn up til about 10 o'clock and we weren't very pleased because we'd been hanging about all that time waiting." (Int19: George cared for his wife)

Then, it could lead to the cancellation of support when a support visit was perceived to be useless. This happened in Mark's situation when the paid carers came at a time when he was sleeping and did not need the visit meaning an opportunity for support was lost in this day.

"Some mornings (they) come on the morning visit and that would be turned about half past eleven because obviously how their day is planned with previous patients and sometimes my mum would say it is not really much point you coming here now he has had his meds and he is fast asleep and there is not a great deal for you to do on the visit…" (Int09: Amanda cared for her father)

This contrasts with Debra who talked about the care arrangement meeting which was conducted with the care company representative while organising the support package for her grandmother. They discussed the different aspects of the care plan and invited the other family members who were sharing the care to comment and adapt it whenever needed.

"With my nan… the lady actually sat with all of us and she went through what her team provide for care, how long each call would be, the times that we were

allocated for care… asked us if there was anything that she wanted them to do or anything like that." (Int14: Debra cared for her grandmother and aunt)

To sum up, the provision of proper support required careful consideration of the caring dyad's needs, routines, and preferences to provide individualised care. However, limiting the opportunities for individualising the amount and type of support to meet the changing needs of PwC made the support less beneficial and increased the FCs' struggle.

5.6.1.b. Ease of access to Support

Having facilitated access to support at the time of need gave a sense of reassurance to FCs that they would be able to cope with the support available to them. However, if access to support was complicated, this resulted in a sense of confusion, vulnerability, and frustration. In this study, support access was governed by various aspects which included the competence and intuitiveness of HCPs to determine the support needs, negotiating bureaucracy to access support and lastly the impact of COVID pandemic on support access.

- HCPs' competence and intuitiveness

The ability of HCPs to determine care needs was important to give FCs access to the support required. If HCPs misjudged the actual needs of PwC, this would limit access to the support needed. Consequently, it resulted in difficulties with coping and FCs' breakdown when care needs escalated. Stephanie felt that the palliative care nurse misjudged her mother's eligibility for paid carers visits due to an incorrect perception of her mother's dependency level. Therefore, Stephanie coped with the

increased caring demands alone which led to a significant level of distress.

"… I don't know what happened but there seems to be something there, some misunderstanding as to at what point do you allow the government-paid carers to come in? And I'd (been) broken by that point." (Int16: Stephanie; care for her mother)

Some FCs assumed that the limited palliative care experience and competence of some HCPs resulted in their inability to identify and respond to the support needs during EoL. For instance, while seeking out-of-hours support for managing Sophia's distress, her daughter Stephanie struggled to negotiate for the required support at night and her complaints were dismissed. Stephanie argued that the inability of the out-of-hours staff on this night to respond properly to her call for support and correctly assess the problem could be linked to the limited competency and knowledge level of the staff. This was evident for her when another nurse who had a palliative care background visited her mother the next morning and accurately identified the problem and responded promptly.

"…this particular nurse had experience with palliative care in a hospice. So she said she knew the difference and what to look for. And I guess that's why it had been missed previously from the other nurses that come." (Int16: Stephanie; cared for her mother)

Similarly, the failure to anticipate support needs could place the caring dyad in significant distress. Jean was suffering from severe pain which was caused by the urinary retention at EoL. However, the lack of anticipation of this problem and failure to approach it with a suitable

anticipatory intervention (i.e., catheterization) led to Jean's experience of suffering and exaggerated pain which placed her daughter Emily in significant traumatic emotional distress.

"Fairly early in the morning … the palliative care team arrived and what they realised was that they hadn't catheterized her as they should have done so actually did (cause) distress and discomfort … the palliative care team apologized and they did agreed that they should have anticipated that earlier…"(Int08:Emily cared for her mother)

By contrast, providing access to anticipatory support at the right time made FCs feel great reassurance and satisfaction. For instance, Stephanie was provided with a night sitter on the night of her mother's death that enabled her to be with her mother at the time of death.

"A good thing with having the open system for the communication is that they could see when somebody's in their last few days of life. So I got a phone call on the day that mum died saying 'Would you like a night-sit?', from the Hospice." (Int16: Stephanie cared for her mother)

Similarly, Natalie expressed her deep sense of reassurance when she was offered the night sit on the day of her husband dying which helped her for experiencing a peaceful end.

"So that night the woman (night-sitter) who came … she was amazing because I needed someone for that night, I was scared because I knew he was dying then…And the reason I was so grateful, and that's why I believe that she was sent for a reason was because I wouldn't have known what to do…It was to see him physical … like she said he's not suffering… and to have someone to say that to me, who I knew had done this so many thousands of times before, was

really reassuring and helped the end of his life to be peaceful." (Int12 Natalie cared for husband)

In summary, HCPs' ability, and competence to identify the existing and potential needs for support were crucial to give FCs' access to the support needed. This created a sense of reassurance and emotional comfort in the face of the chaotic caregiving and prognostic uncertainty.

- Negotiating bureaucracy to access support

The need to negotiate bureaucracy to access support was experienced widely in the present study and it acted as a barrier to getting proper support at the most appropriate time. This was influenced by three factors: complicated access procedures and rigid regulations; support fragmentation, and the limited availability of services. For instance, some FCs stated that the process for accessing support was lengthy and stressful. Maria talked about her experience of contacting a palliative care nurse through the single point of access.

"My biggest problem that I encountered and this is horrible … if I needed a palliative nurse I had to go through the telephone system from single point of access… You have to go through the whole story from start to finish … Then they triage that phone call and then you wait… I think there should be an easier way of getting in contact with them." (Int11: Maria; cared for her husband)

By contrast, a sense of relief and reassurance was felt when FCs were given straightforward access to support without being overwhelmed with complex bureaucratic procedures. In her interview, Stephanie reflected on her positive experience with the single point of contact which facilitated her access to support rather than using the standard routes for

health services access which could be confusing and resulting in delays to support.

"So it was only then that you felt some relief, when they came out and they gave us a leaflet and said no more 999, no more 111, you can phone this number… That then was sort of relief that we didn't have all that chasing, questions for hours on the phone." (Int16: Stephanie; cared for her mother)

Issues related to rigid regulations were experienced by some FCs regarding pain management. If PwC needed extra pain relief over the usual regimen, then the access to extra pain medications required two authentication processes which delayed pain relief and increased the caring dyad's distress and suffering which stated by Olivia.

"…they can still only administer a certain amount and they've still got to go over, if they believe they need to administer more they've then got to phone and get permission. And then you're having to wait for the supervisor to come out to sign the paperwork to say yes you can give them that extra. It's very distressing; it is very frustrating…" (Int13: Olivia; cared for her mother and her sister)

In another scenario, the rigid regulations hindered access to support in an emergency. Jack developed severe symptoms and needed admission. However, his daughter Abigail struggled to refer her father to a medical facility during an out-of-hours period. She assumed that happened because her father was a palliative care patient, and the referral was needed to be made by the hospice during the working hours. As a result, Abigail felt vulnerable and insecure keeping her father at home while not being able to access urgent support when needed.

" … So we just felt like it was not safe to keep him at home. So that was quite frightening really, quite frustrating that you can't get him … he just really needed to be in a hospital being monitored … but we couldn't get him in there." (Int20: Abigail cared for her father)

Negotiating the bureaucratic process of support also involved dealing with the issue of fragmentation of services and non-unified system of support. This led to complications accessing support and difficulty in the arrangement of support packages for PwC. This triggered FCs' confusion. This was illustrated in Debra's narratives. When her grandmother's Ann pain medications ran out during the out-of-hours, Debra wondered about getting the pain medications from the nearby hospital. However, Debra was astonished when the visiting staff told her that was not possible because her grandmother's care was under the GP responsibility and support.

"… I were like you've got a hospital on the doorstep with enough medication that we need and I just cannot understand how you can't just go to the hospital and get that medication from the pharmacy. But it's because it's a GP prescription…once again that's red tape." (Int14: Debra, cared for an aunt and a grandmother)

Geographical variations in service provision added to the confusion of FCs. This was especially the case where the PwC was relocating. This was experienced by Stephanie when her mother moved to be cared for at her daughter's house.

"… there was lots of talk about Macmillan nurses but the district nurses are sponsored by Macmillan in that area where mum lived but over here they're not.

We haven't got a Macmillan, it's the hospice, it's very much the hospices that come out. So it's a very … Marie Curie, there was lots of talk of Marie Curie but that isn't in this area, it's sponsored by somebody different. So again it's a little finding out … can be a bit daunting." (Int16: Stephanie; cared for her mother)

The challenges of services variations and poor coordination impeded prompt access to support which was described by Stephanie as ***"Postcode lottery of services".***

"…one of the really big issues for us was postcode lottery. Because my mum was in (place of residence), which is a different area to where I am and it was getting those areas to communicate. And that really delayed getting the right support in place." (Int16: Stephanie; cared for her mother)

Poor communication and coordination between services provoked FCs' distress due to continually chasing and negotiating for getting the support they needed for PwC. In the following narrative, Laura described her experience of chasing for arranging the support for her mother.

"Just a lot of the time it just felt crazy that I was having to chase and ask and at times beg for help. And it definitely seems like the left hand wasn't speaking to the right hand at times. And it was, felt like I was going round in circles and it was just like I just need somebody to help and to do this. And it felt like yeah, it was a challenge." (Int15: Laura cared for her mother)

It was clear that poor communication and coordination between support services created a barrier in support access for FCs who were already dealing with other commitments that contributed to their sense of chaos as described in Section 5.5.2. When difficulties were experienced, this increased the sense of a chaotic caregiving experience. In her

narrative, Barbara signposted this issue when talking about her difficult experience of negotiating and coordinating the support for her mother.

"I found that incredibly frustrating that nobody was communicating and then such a time where while all of this is going oh I am still trying going to work I am still have my own home and family to look after as well so to have to ring them for the fourth time or to say no we have sorted this such and such we have done that it just got messy…" (Int02:Barbara cared for her mother)

Negotiating the bureaucratic process of support was affected by issues of service availability. For instance, the limited availability of certain out-of-hours services in some localities placed the caring dyad in a great distress. Debra talked about her experience with the limited out-of-hours pharmacy facilities in their area.

"There's a lack of out-of-hours facilities shall we say. If you need something during the day and you've got a chemist open and you've got the doctors open and things like that, it's quite easy to get prescriptions changed … And it's heart-breaking to watch somebody you love that's obviously dying in a lot of pain. And there's very little you can do about it." (Int14: Debra; cared for her grandmother and her aunt)

This also was the feeling of Abigail about the services when she was caring for her father and faced in difficulties support access.

"… I don't know if it's whether it (support) could be more or just because there's shortages and you know, shortages in services everywhere that there aren't the things in place that should be that they're saying there are, you struggle to get it." (Int20: Abigail cared for her father)

By contrast, other FCs expressed their emotional relief when HCPs were available for support and help which gave them a sense of togetherness and reassurance about the support accessibility. This was evident when a hospital specialist nurse shared her contact details and emphasized her availability for help and deal with access bureaucracy which was mentioned by Amanda who cared for her father with her mother Heather.

"…she (hospital specialist nurse) would give her number to my mum and said you can phone me any time of the day any day of the week … if my mum was unsure of anything I think text and called her quite a lot and she was a key part in properly keeping my mum together through it all …" (Int09: Amanda cared for her father)

Similarly, this was experienced by Laura in her interaction with the hospice support team while she was caring for her mother. The availability of specialized and skilled support from the hospice with unconditional accessibility gave her the sense of reassurance and emotional relief.

"…they would had (hospice) the specialists in terms of offering support but particularly for … they had specialists in that particular type of cancer as well. And I think that was really important. … I guess it's knowing that there's somebody there that you can contact and that they are the most informed … that they can be to actually help you in your particular situation." (Int15: Laura, cared for her mother)

The availability of support maximised FCs' confidence in their ability to cope with caregiving journey. This was reflected by Natalie in the following narratives.

"…So it's building up the carer's resilience and strength and belief that it is okay, you can do this with that right team around you." (Int12: Natalie cared for her husband)

In summary, FCs in the study engaged in a negotiation process of support access bureaucracy which in many times either limited or delayed their access to the needed support. This in turn contributed to their sense of confusion and vulnerability in their support interactions rather than reassurance and emotional relief.

- Impact of COVID pandemic on support access

In the context of this study, the COVID pandemic added further uncertainty, confusion, and complexity regarding support access. For instance, the access to in-person support visits was limited and transformed into remote consultations whenever possible which was mentioned by Abigail in her narratives.

"I think because of the COVID regulations it's been very, very unclear and very … no-one knows what's happening. Obviously the district nurses and the Macmillan nurses will try not to come into the property because everyone's trying to social distance. So it was just as and when really. It weren't very frequent… So a lot of it was over the telephone…" (Int20; Abigail cared for her father)

Similarly, other FCs mentioned the lack of accessibility to some support resources which they used to utilize before the COVID

pandemic. Olivia talked about the closure of well-being centres which she used mostly for getting information and support. This made her feel lost while trying to access support during the COVID pandemic.

"But you then had COVID, so there's nowhere for you to go… you don't know who you can phone, you don't know who to talk to. And to be quite honest, you also would make a phone call and it would be due to COVID, I'm sorry we're not in the office." (Int13: Olivia, cared for her mother and sister)

Furthermore, the existence of the COVID pandemic affected the access to paid carers visits for some FCs. Amanda talked about their experience with recurrent cancellation of paid carers visits during the COVID pandemic which increased the existing stress and uncertainty during this time and provoked the sense of emotional vulnerability.

"I think it just added to the frustration it was always stress time everything was heightened have they of shown up unattended it would of put as little bit as pressure on my mum and it wouldn't have given her some reassurance to have had a skilled person." (Int09: Amanda; cared for her father)

This contrasted with one FC who reported the normal running of HCPs' visits for her mother when she was asked about experiencing any change in support services during the COVID pandemic.

"No, it was just on the same things." (Int04: Amy cared for her mother)

However, Amy acknowledged that the HCPs used to call and visited them whenever necessary during the COVID pandemic.

"...they do a phone call and then every couple of weeks they were coming in and doing face to face and have a proper catch up and then keep on top of it with a phone call." (Int04: Amy cared for her mother)

In summary, the COVID pandemic affected the nature of FCs' access to support in several ways which made some of them felt vulnerable while trying to support PwC at home during this unprecedented time. Lastly, throughout the FCs narratives in the previous codes, it was apparent that facilitated support access was essential for developing the sense of reassurance that counteracted the experienced chaos of caregiving journey. However, when access was hindered by HCPs' incompetence to identify the needs; support access bureaucracy or the impact of the COVID pandemic, it led to increased level of confusion and emotional insecurity.

5.6.1.c. Timeliness of support

Timeliness of support was crucial in minimising the sense of chaos and confusion during the caregiving journey. If support was provided in a timely manner, it yielded reassuring and favourable experiences of emotional relief and security. However, when delays were experienced, a profound feeling of vulnerability, emotional insecurity, and loneliness existed. The significance of the timing of support response was interpreted in several support situations in the study. For instance, Jennifer stated the importance of timing in her reflections about the recommendations for improvement of the support services.

"Time was absolutely of the essence… yes, timeliness is really important." (Int07: Jennifer cared for her husband)

Generally, delays in support response were experienced widely in this study. In the first instance, this was evident in delayed information provision and preparation for caregiving. When this occurred, FCs were left confused and used a trial-and-error approach which resulted in care errors in some instances. This was apparent in Stephanie's narratives about her experience of hospice information and advice.

"… the hospice were going to show you different things with mouth care, things like that ., but it was too late at that point really. I'd been doing things wrong with the sponge." (Int16: Stephanie, cared for her mother)

Other case scenario of delayed support was attributed to equipment provision which limited the opportunity of PwC to benefit from this support which was reported by Jennifer in her narratives about the equipment provision for her husband.

"… we got a bed, a proper bed downstairs with a proper mattress on it, etc. I don't think he ever slept in that actually. I think it was too late. So things like that were too late, he needed that help before …" (Int07: Jennifer cared for her husband)

Meanwhile, Amber reported a significant delay in setting up the care visits for her mother.

"...they (the GP)said we will make a referral for you actually having weeks and weeks for that referral or potentially not even here and back and forward and having to go back again and again." (Int03: Amber cared for her mother)

However, when there were delays in setting up support services following discharge from hospital, FCs felt threatened and their

confidence to cope with caregiving would be diminished. This was the case with Marilyn who experienced significant delay in arranging the care for her husband following the hospital discharge.

"… it should have been automatically that the Macmillan nurses or something, palliative care or whatever, should have been in place straightaway…I was terrified, I was terrified for Andrew, would I manage? It was awful… So I feel that when people are sent home and they know it's going to be the end of their life, things should be in place immediately. No-one should be left to it." (Int22: Marilyn; cared for her husband)

Additionally, service provision was not always preceded by an assessment of the individual needs of PwC. In this context, Heather reported that her initial meeting with the homecare team leader who was responsible for organising her husband's care package was delayed for several months. This resulted in the failure to provide individualised support for her husband.

"… I got a phone call from the agency where the carers came from telling me that the manager is coming out to see you at 12 o'clock tomorrow to discuss your care package. Now that was after I'd had carers for nearly three months. … I never got to meet this guy. He left it too long to come and see me." (Int10: Heather cared for her husband)

Similarly, the delayed removal of support provided such as supportive equipment at home would cause significant distress for FCs, once PwC died which was mentioned by Jennifer in her following narratives.

"It did take a little while for them to remove the stuff … I didn't use the room that it was in, I just kept the door closed … because we'd got this space I suppose we were fortunate in that respect. Having got a very small house ...that would be quite distressing." (Int07: Jennifer cared for her husband).

Additionally, delayed support made FCs feel helpless and experienced a significant level of distress and loneliness if this was related to symptom management - an issue which tended to cause PwC suffering. Emily struggled to get support for her mother's pain until the next morning which was a horrible experience for her.

"We were very alone that night and it was long night it was started my mothers' pain Saturday 11:00 o'clock in the morning and we did not get actual help out until four o'clock in the early hours of the next morning by the time…" (Int08:Emily; cared for her mother)

When FCs failed to get prompt support at the time of need, this resulted in a sense of despair and giving up. For instance, Heather lost hope of getting timely support for dealing with her husband's agitation, when each time she called for support, it arrived so late to the point it was useless.

"… Another night I was dead on my feet, it was about midnight and he was ….still throwing things about and I couldn't stop him. And so I rang … it was after midnight and they came about half past 2 in the morning. But again when they got here he was asleep, so they just left. So if it happened again after that, which it did, I just sat there and wore myself out with him… So I didn't ring them anymore." (Int10: Heather; cared for her husband)

In some caregiving situations, delayed support was attributed to staff shortages which was alluded to by Debra.

"The team that work at night, the on-call team, are so far-stretched, they've got so many people that they're looking after and families that they're looking after and patients, that sometimes you can be left for up to two hours before they arrive. And that's through no fault of their own, that's not their fault, that's a lack of funding and staffing for out-of-hours care." (Int14: Debra cared for her grandmother and her aunt)

The COVID pandemic was another factor that affected the speed of support response. Maria who provided care during the pandemic linked the delay in support response to the existence of the COVID pandemic and the imposed pressure on the services.

"… it's made a lot worse now because of COVID. You can be on that phone for 20 minutes, half an hour and then they'll say if things get worse and you need to speak to us, this is my name, ring us back…" (Int11: Maria; cared for her husband)

By contrast, some FCs received support in a timely manner which triggered a great sense of relief and reassurance. This was evident when Stephanie experienced a quick access to equipment which facilitated her mother's stay at home.

"… that (getting the hospital bed) was a relief for us all…the equipment, they were very fast in getting equipment in and sorted out." (Int16: Stephanie cared for her mother)

To sum up, getting timely support response embraced a sense of FCs' reassurance. However, when delays in getting support were

experienced, this increased the sense of distress which exaggerated the existing uncertainty and chaos of providing EoL caregiving for terminal cancer. It was evident in FCs interviews that having feasible access to individualised support at the proper time had a significant impact on FCs' sense of reassurance and emotional relief. However, if this was hindered, it led to the experience of emotional vulnerability and distress.

5.6.2. Engaging in meaningful relationships with HCPs

The relationship between FCs and HCPs was the second component of the experiences of formal support which either elicited a sense of reassurance or confusion and vulnerability. When HCPs developed a meaningful relationship with FCs, this empowered them to cope with the journey of caregiving and beyond. However, if relationship disruption occurred, this resulted in significant emotional distress and frustration. Meaningful relationships with HCPs were experienced and built on three pillars which included showing compassion and establishing rapport, engaging in open communication, and sharing the journey of caring and mentoring FCs.

5.6.2.a. HCPs showing compassion and establishing rapport

Non-compassionate care was experienced by some FCs in the study when HCPs did not display an interest in their relationship with the caring dyad. One form of this lack of interest appeared when FCs felt that they were being dealt with as a caseload and not as an individual. For instance, Heather reported that some visiting paid carers did not engage in any kind of communication with her husband and only performed the care through their actions which lacked compassion.

"… they'd come in and they'd literally treat him like a lump of meat, turn him over, change him, give him a wash and wouldn't even talk to him." (Int10: Heather cared for her husband)

Other FCs perceived that the visiting HCPs lacked the proper consideration of the FCs' emotional context. This was perceived as a lack of interest and respect for their situation which deprived FCs of the reassuring human caring relationship with HCPs. This was reported by Natalie regarding the attitude of some HCPs during the care visits in which she felt that they did not pay her the required consideration and respect.

"But they were really grumpy, they wouldn't even smile. And then they'd put their PPE on and you'd hear them chatting outside." (Int12: Natalie cared for her husband)

Furthermore, in another part of my conversation with Natalie, she perceived that her unsatisfactory relationship with some HCPs would be attributed to their lack of emotional intelligence to deal sensitively with the family situation. Natalie felt that this deprived her of a possible opportunity for emotional support.

"I think she (Macmillan nurse) just didn't have the emotional intelligence to read the family well enough and she was condescending." (Int12: Natalie cared for her husband)

"… that could have been an opportunity for emotional support for me, it could have been but because we didn't connect I kept it business, I wasn't interested." (Int12: Natalie; cared for her husband)

Family carers noted that the potential for rapport and mutual understanding was threatened by having different HCPs involved in the care. This provoked a feeling of confusion and vulnerability. In the situation of Patricia, she received care visits from different unfamiliar HCPs. Her daughter Doris considered this as suboptimal and not suitable for developing the required rapport.

"I had a lot of concerns about the care providers for the first few weeks because she was getting a different person every day, literally a different person every day, which when they're providing personal care is not really ideal." (Int24: Doris cared for her mother)

Having different HCPs was as a barrier also for other FCs to establishing a care bond and rapport, and lead to the refusal of support from those being cared for. Eric did not like the care support visits which he received from multiple HCPs and his sister Carolyn thought that rapport needed time to be developed and such familiarity was essential in the caring relationship. If this was possible, trust and confidence between related parties would develop over time and the support was then accepted.

"…I think in the care profession, I think they need … to have that bond for the care … if they had a couple (Paid carers) what did it, that's how you get more done … You open up more and you can do a bit more personal care. Whereas if you have a stranger coming to the house, you're not going to let anybody do anything for you…" (Int25: Carolyn cared for her brother)

By contrast, compassion and rapport were established effectively in other caregiving situations in the study. Maintaining the dignity of the

PwC and showing interest in the care process was a crucial aspect of compassionate care for FCs. Maria spoke of how paid carers dignified and compassionate attitude towards her husband's care made her feel emotionally relieved and satisfied.

"… the care company, the ladies that came here seriously I've got so much respect for them… but why I'm saying that is those carers helped him keep his dignity, so professional." (Int11: Maria cared for her husband)

Another example of delivering compassionate care and developing rapport appeared in the intuitive attention and response to FCs' emotional breakdowns. This was evident when a paid carer realised Heather's emotional burnout and stayed with her for reassurance beyond the duty time.

"Some of them were dedicated to their job and would go above and beyond. There was one particular couple of ladies that used to come and it was half past 9 one night when they were leaving and they could see I was upset because I knew I was in for another bad night. And they came and put the kettle on and they sat with me in my kitchen and had a cup of tea with me. After hours, they were off-duty, they'd finished but they actually stayed for half an hour with me and had a cup of tea with me." (Int10: Heather cared for her husband)

In summary, dealing with compassion and establishing rapport with the caring dyad was a cornerstone of developing a meaningful caring relationship with HCPs. However, if this was inhibited by limited empathetic skills and non-sensitive organisation of care delivery, it would hinder the support utilisation and increase the FCs' sense of confusion and distress.

5.6.2.b. HCPs engaging in open communication

Engaging in open communication with FCs was a crucial aspect of developing meaningful relationships with HCPs. If open communication was developed, it would lessen the sense of apprehension, confusion and vulnerability experienced during the chaotic caregiving journey. Two features of open communication were reported in the study which included maintaining clarity and the provision of information.

- Maintaining clarity

The importance of communication clarity was expressed in several narratives of FCs in the study. For instance, Daniel expressed his wishes for a clear and open communication regarding the time of hospice referral to achieve his wife's advance care planning wishes of dying at the hospice.

"... my biggest hope is that they will be honest and open enough to actually say when that time comes that you should be now in the hospice rather than at home. Rather than leaving it to us to decide." (Int17: Daniel cared for his wife)

Family carers preferred clear communication which would help them to make informed decisions. However, if the communication lacked the expected clarity and communication ethos, this would result in significant emotional distress and confusion for FCs. For instance, Laura narrated her experience of receiving her mother's diagnosis which was unplanned and occurred by chance.

" We had issues around the way that the diagnosis was given … nobody actually spoke directly to my mother, it was through a conversation …that one of the registrars said 'Oh, this is common in people with your mother's type of

problem'. And I was kind of a bit perplexed and said 'Well what is the problem because nobody's actually said?' And he said 'Oh it's pancreatic cancer'. But it was to me, not to my mother and that was the first kind of mention of pancreatic cancer." (Int15: Laura; cared for her mother)

Frustrations and emotional shock would be experienced if prognosis was communicated unclearly. Some FCs had an experience of misleading communication of prognosis that led them to inaccurate interpretations and expectations and a sense of confusion. For instance, Olivia talked about her experience with communication of her sister's prognosis which did not reflect the actual situation.

"…So we sort of had quite a few months but how it (Communication of prognosis) had been put over to us was that she could have a number of years…" (Int13: Olivia cared for her mother and her sister)

Similarly, Rose reported about the unrealistic information which was communicated to her friend Brian about his disease progress. Then, she had to deal with his upset and frustration when he faced the reality regarding his prognosis.

"We all felt that it was sort of information that had just not been shared properly. And that he'd been let-down by that. I think that the big thing that affected (Brian) more than anything was the way he was led to believe things were so positive by his consultant. I think if she'd been more honest, then he wouldn't have come crashing down from such a height because he would have been better forewarned that things weren't actually going that well." (Int26.1 Rose cared for her friend)

Other forms of unclear communication were related to support expectations. It was apparent that clear communication about support such as, the timing of visits was important in FCs sense of reassurance. However, if this was lacking, it increased their uncertainty, distress, and frustrations. This was echoed in Amanda's narratives about the paid carers' visits to her father when they used to come without notice.

"I don't think there was much communication I think you knew when they coming when they knock on the door they would just say we would be back for the next visit and they would say we can't give a time …" (Int09: Amanda cared for her father)

Heather added that in some instances, the support visits were declined without any prior notice or communication during the COVID pandemic which triggered her sense of frustration and upset about waiting for support that did not came.

"… And twice they let me down when they said they were coming and they just did not turn up and nobody rang me to tell me why." (Int10: Heather cared for her husband)

On the other hand, support visits which were conducted without prior communication would increase FCs vulnerability and distress. This was also experienced by Heather when a night sitter came without any prior notification about the visit. This made her feel vulnerable throughout the night and deprived her of proper night sleep and respite that was offered.

"… this guy came and I went to bed and I actually took my iPad and my phone to bed with me and I actually messaged my sister because I was so frightened…

But the following morning, well I was up about half past 5, I couldn't sleep and I made him a drink and he was very polite and very sociable. But I'd no warnings of him." (Int10: Heather cared for her husband)

Conversely, a great sense of relief and satisfaction was experienced if HCPs engaged in clear and honest communication with FCs. Amy described her appreciation of clear professional communication with the visiting nurses about her mother's prognosis which triggered her feeling of emotional relief.

"... they were very upfront which we are preferred because mum had been ill for so long they didn't … mask over it or make it sound any nicer than what it was and they didn't which was lovely they were very professional but also very kind and caring and gentle with it but they didn't hold back the truth which was greatly received from us." (Int04: Amy cared for her mother)

Similarly, this sense of reassurance was felt when clear open communication about support expectations and visits was experienced. For instance, Rose appreciated their clear communication with the visiting staff regarding the time of visits.

"Whenever they made an appointment to see him, they would be very open and say, it'd be about 12 o'clock but you know, I may be a bit late. Because they'd spend time with each person. And none of us minded that and 'Brian' himself actually said 'Oh, (Visiting staff) 45 minutes late, never mind, she must be with someone who needs her. Next time she's late it might be because she's with me and she's late for the next person." (Int26.1 Rose cared for her friend)

Then, FCs were reassured that they had access to support at a particular time frame. In another caregiving situation, Heather

appreciated the hospice communication about providing a night sitter for her so that she was expecting this support which made her feel reassured.

"… two nights later, I got a phone call from the Hospice Service telling me that they were sending me a night sitter that night. I said 'Oh thank you for letting me know', she says 'Yes, she'll be there about 9 o'clock'. And they told me her name, who to expect…" (Int10: Heather cared for her husband)

To summarise, engaging in clear communication was significantly important. Hence, it created a context of reassurance and emotional relief in the chaotic caregiving environment. However, if this did not occur, a sense of confusion and vulnerability would result.

- Provision of Information

Provision of information was the second aspect of open communication which was evident from the interviews. When HCPs provided FCs with the necessary information such as disease progression and caregiving practice, this limited their sense of confusion and vulnerability. However, if the process of informing was not a part of HCPs' communication, FCs felt lost in their chaotic caregiving journey.

Throughout various caregiving situations, FCs expressed their intense need for information especially regarding the support available to help them. Olivia commented:

"... I think at times people need to actually approach them and say this is the help you can have. There's nothing wrong with needing this help or asking for this help." (In13: Olivia, cared for her mother and her sister)

Indeed, if FCs had access to adequate information, this enabled them to determine their level of caregiving manageability at home. This in turn help them to make informed decisions regarding the place of care as stated by Olivia.

"I just think it would make people's lives so easy, it would make it easier, it would help them make decisions that they need to do, help them decide will I do in a hospice … do I prefer it if the family would do it?" (Int13: Olivia, cared for her mother and her sister)

However, a number of participants reported having to chase HCPs for information. For instance, Abigail talked about her deliberate efforts to follow up on her father's condition and get information from HCPs.

"Sometimes I'd have to … off my own back I've rang the lung nurses at Hospital and got information off them or I've had to ring the Macmillan nurses myself." (Int20: Abigail, cared for her father)

This was similar with Stephanie who described the reluctance of HCPs in communicating information about her mother's prognosis and possible deteriorations and challenges. She perceived that HCPs tried to lighten the situation which was against her wishes.

"… a lot of the time I had to say tell us what to expect, what behaviour with this being in the brain, what could happen? And it's very much like they don't really want to tell you… we were very much wanted that honesty and had to dig really to say what can we expect." (Int16: Stephanie, cared for her mother)

In other instances, it seemed that FCs got information by chance suggesting that there was not a clear process for informing. In the

situation of Laura, she was advised to apply for financial support for her mother. However, she found later by chance that she was also entitled to carers' allowance.

"… they suggested or recommended that mum apply for attendance allowance. And through kind of I guess Googling I found out about carer's allowance as well… that wasn't anything that was again talked about or mentioned by the hospital as something that we could access." (Int15: Laura, cared for her mother)

Limited communication of information made FCs feel uncertain about their own ability and whether they were doing the correct or wrong care practices. This was stated by Abigail when she talked about her experience with insufficient information about her father's support needs.

"…I felt very much as if I was sort of like winging it as to am I doing the right thing? Am I doing everything that I should be doing?" (Int20: Abigail, cared for her father)

Similarly, this of lack information made FCs feel overwhelmed and distressed while trying to cope with caregiving. Olivia felt as if she was **"*Drowning"*** while she was dealing with the caregiving situation. This illustrated the extent of psychological distress which FCs experienced while trying to adapt to caregiving in the context of limited information.

"There's sometimes it felt as though we were drowning because we didn't know what to do, we didn't know where to go." (Int13: Olivia, cared for her mother and her sister)

Lack of communication of information about support expectations led to an assumption that support was solely for PwC and losing possible support opportunities for FCs. This was happened with Heather when she felt embarrassed asking for help with household tasks, considering that these activities were out of the paid carers support scope. However, she realised later that the paid carers support entitled her to this kind of help.

"… I did actually ask them to change the bed because I couldn't manage it on my own and one of them hoovered up for me. And I felt terrible asking them. And they said 'No, that's what we're here for'… And I didn't know they were allowed to do that til these two particular carers told me after a couple of month of having them four times a day." (Int10: Heather; cared for her husband)

It was clear that provision of clear and meaningful information to FCs prepared them for their caregiving journey. Likewise, Laura described her experience of the hospice information sessions which facilitated her coping with her mother's illness at home.

"… they (the hospice) had like drop-in sessions on a weekly basis… So we did go a couple of times to ask about medication and they were brilliant in terms of actually, explaining what the different medication did and the kind of slight subtle adjustments that were made that made a big difference to her actually being able to be at home" (Int15: Laura, cared for her mother)

When HCPs effectively communicated and explained information to FCs, it embraced a sense of emotional relief and reassurance for them which was narrated by Amy.

“There always that something come up with another deterioration of mum or another side effects and having them (Nurses) come in and explaining what it was and what is related to was an immense help... it was a great relief that’s for sure.” (Int04: Amy; cared for her mother)

However, another crucial aspect of the informational experience of FCs in the study was their need for repetition and follow-up of information. FCs explained that by the fact that their information processing and interpretation were altered due to the context of distress and uncertainty which is associated with EoL caregiving. This was evident in the following narratives of Olivia and Stephanie.

“… if they understand that when you’re talking to family members, family members have got to process this information. But you’re not giving them time to process it. It’s as if I’ve already told them, I’ve explained it to them, that’s it. No so the next day reiterating it, saying you do know that, you do realise, you did hear what I said?” (Int13: Olivia, cared for her mother and her sister)

“…you are so stressed that you need to be told twice… because you’d forget, I thought oh I remembered some but then you forget. So it’s something that you need.” (Int16: Stephanie, cared for her mother)

Hence, written information was suggested as a possible reference resource to support FCs as stated by Olivia.

“… if we’d have had a little booklet … so even to the point of saying there’s this organisation there, there’s this charity organisation there if you need help.” (Int13: Olivia, cared for her mother and her sister)

To summarise, provision of information was important to minimise the chaotic experience and confusion of the caregiving at EoL. It was

apparent through the reported codes that engaging in open communication was an essential pillar of meaningful relationships with HCPs which could be achieved through maintaining clarity and provision of information. This in turn would result in developing the sense of emotional relief and reassurance.

5.6.2.c. HCPs sharing the journey of caring and mentoring FCs

Sharing the journey of caring and mentoring was a building block in establishing meaningful relationships between HCPs and FCs which made them feel reassured and accompanied. This sense of shared journey was accomplished when FCs were acknowledged as care providers and at the same time as care recipients. The concept of sharing the journey was embraced through three distinct aspects which included maintaining regular checking of FCs, involving them in the care process and encouraging them and acknowledging their efforts in caregiving.

- Checking and maintaining contact

Checking and maintaining regular contact with FCs was an important facet of sharing the journey of caring to develop their sense of reassurance. However, it was evident through interviews that some FCs had an intense need for HCPs' checking and contact. For instance, although Jennifer felt that she was able to cope with her husband's care, she expressed her need for HCPs' checking.

"We coped very well I think. But even those that appear to be coping, just need that check-in and that was missing." (Int07: Jennifer cared for her husband)

Similarly, Donald mentioned that HCPs' checking is crucial in developing a feeling of acknowledgement.

"… it's just to say are you okay, are you coping? And I say yes I'm okay, yes I'm coping, thank you very much… That would be at least I've then been acknowledged that I exist …" (Int18: Donald was caring for his wife)

On the other hand, if checking and follow-up were missed, it made FCs feel lonely and helpless. Marilyn was unsure about her ability to cope with her husband's care after he was discharged from the hospital. She felt lonely and vulnerable when she experienced a lack of HCPs' follow-up on her coping, manageability, and wellbeing.

"…no-one should just be abandoned and let to it with someone so poorly… People need a follow-up not just kicked out of hospital and just left to it." (Int22: Marilyn cared for her husband).

Furthermore, the lack of HCPs' checking, and contact triggered a sense of ignorance and exclusion from care and that only the PwC was the focus of concern. This in turn increased FCs' frustration which was apparent in the narratives of Jennifer.

"… I was the carer, yeah, I just feel … can't ignored I suppose. Yeah, I put myself in the caring role and got on with it." (Int07: Jennifer cared for her husband)

Conversely, when FCs in the study experienced regular HCPs' checking and contact, this created a sense of reassurance and emotional comfort. For instance, Natalie talked about her experience with the palliative care team contacting her and checking in which enhanced her emotional well-being.

"…it (was) just my emotional wellbeing… some of that was contained with Palliative care consultant and the team… You just get into this pattern of everyone ringing you all the time and coming round to the house, so that was contained." (Int12: Natalie cared for her husband at home)

This emotional comfort and reassurance originated from FCs' feelings of being accompanied in their chaotic journey and were not alone. In her narratives, Victoria described the impact of the GP's regular contact which empowered her to cope.

"… he (GP) used to call every Monday we did not ask him he just call to check on things he was he was a life saver in many ways… because you needed somebody to tell them what have been going up in the week." (Int05: Victoria cared for her husband)

Maintaining regular checking and contact helped in tackling the implicit urgent need for support and intervention which was underestimated by FCs. In the case of Heather, the hospital nurse specialist who used to contact and check on her identified her intense emotional struggle and referred her for an emergency counselling.

"Well, what it was, (Hospital specialist nurse) recognised that I was struggling in the conversations we were having. And she said would you let me refer you to a psychologist?" (Int10: Heather cared for her husband)

Indeed, the experience of checking and contact was evident throughout the caregiving journey and beyond. Bereavement checking and contact were also considered important and beneficial to FCs in the study. Since, it appeared that FCs underestimated their support needs until PwC died which was mentioned by Debra in her following quote.

"… when you're in the moment you don't accept that you yourself need something because I think your main priority is the person that you're losing." (Int14: Debra; cared for her grandmother and her aunt)

Therefore, FCs felt appreciated and acknowledged when they were contacted after their conclusion of their caregiving journey. In her narratives, Olivia talked about the checking call, she got from a nurse who dealt with her sister's care, and she helped her to get the counselling that she needed.

"… I got a phone call from the nurse who dealt with my sister's pain medication and stuff like that, so I just got a phone call out of the blue asking me how I was doing, how I was feeling... She actually organised bereavement counselling for me through the hospice." (Int13: Olivia; cared for her mother and her sister)

By contrast, if FCs lacked bereavement checking and contact, this led to missing the emotional support necessary to help them dealing with their grief. In her interview, Amy talked about her grief experience when she lost her mother. She lacked the HCPs checking and contact which could have helped to deal with her grief.

"I think I would have appreciated a bit more contact or information on grieving and what I could do because it feels like especially with the lock down when mum passed away I literally went home to an empty house my kids were at their dad's but no family around me and I literally came home and I was by myself and I think that the reason why I didn't start and grieve and up until recently is I just I didn't have the emotional support around me where I could just let it go." (Int04: Amy; cared for her mother)

In summary, HCPs' checking was a crucial aspect of sharing the journey of caring with FCs. If it happened, it yielded a great sense of reassurance and emotional comfort. However, when FCs lacked regular follow-up, it made them feel ignored, lonely, and vulnerable.

- Involving, respecting, and encouraging

It was apparent that FCs in the study valued the consideration of their views regarding the care of PwC depending on their familiarity with their needs and preferences. Carolyn echoed this in her narratives about the importance of FCs' involvement.

"…you've got to listen to the family more you know. Yes, they're professionals, yes they've got a job but sometime you'd want them to go down their… professional, they've got to listen to the family. Because we know him more than they do you know, we know his likes and dislikes, we know what he's like." (Int25: Carolyn cared for her brother)

Family carers' involvement in care required negotiation and adaptation of HCPs' roles and responsibilities within the home environment whenever necessary. If this occurred, FCs developed a sense of appreciation and control over their environment. Some situations in the study indicated the transformation of relationships dynamics between FCs and HCPs. For instance, Natalie was offered a night sitting, however, she felt that the presence of this service would limit her time spent with her husband. However, support was adapted in a way that considered Natalie's preference as such the night sitter was only involved when it was necessary and required.

"… I was like 'I'm not leaving him' and she said 'No, they'll do what you want them to do, it's not … they're not going to come in and take over'. And that was really important that they didn't come in and take over…" (Int12: Natalie cared for her husband)

Respecting FCs views gave them a sense of reassurance that their caregiving was going in the right direction. This was experienced when HCPs validated FCs' concerns. This was narrated by Stephanie who felt acknowledged and relieved when a district nurse validated her concerns regarding her mother distress and made a visit following a full night of distress and suffering when her complaints had previously been ignored. This made Stephanie realised her correct perception of her mother's complaints which was confirmed by the district nurse's attitude.

"So, I phoned again in the morning and a wonderful district nurse came out and sorted everything out. And she went above and beyond what I believe others would have done. And she said that we need to get on top of these secretions because it can get too late where we can't do anything. I thought goodness me." (Int16: Stephanie cared for her mother)

This embraced a great sense of respect for FCs' knowledge and made them feel as HCPs' partners in the care process which was illustrated by Natalie.

"They (Palliative care team) didn't treat me like I was stupid because I knew all the drugs he was on, I knew everything he was on. I knew when he needed to take it and even… and they valued us…" (Int12: Natalie cared for her husband)

Other form of involving and respecting FCs was acknowledging their efforts and providing them with empowering encouragement. If

HCPs acted as FCs' tutors who respected their caregiving achievements and provided them with encouraging comments, this gave them a sense of reassurance and reward which was reported by Victoria and Natalie in their following narratives.

"… when he (GP) knew Robert died and said you know Victoria you did well we all said how well you done and that thing should I know but at that time it just don't felt through really but you think back on it." (Int05: Victoria cared for her husband)

" But just to have someone there to say everything you're doing is right was all I needed. And that's what they did, sometimes they just said 'You're doing a great job, that's it, there's nothing else that you can do that you aren't trying already." (Int12: Natalie cared for her husband)

On the other hand, if FCs were viewed as external agents and lacked this involvement in care, this made them feel helpless, inferior, and frustrated. This was experienced by multiple FCs in the study. For instance, when FCs were not involved in the communication about PwC's condition, this increased the confusion and frustration they felt. In her interview, Abigail talked about her lack of involvement in the communication process regrading her father's condition which made her felt confused and upset.

"… they'd ring my dad and obviously I wasn't there and they'd ring my dad and speak to him and sometimes due to just tiredness or confusion or you know, medication, he didn't actually relay the information to us. So it was quite confusing at times. Quite frustrating that I wasn't aware what was happening." (Int20: Abigail cared for her father)

In some situations, FCs' involvement in communication process were interrupted because of contextual factors which limited their engagement. For instance, hospital visits regulations during the COVID pandemic deprived Donald from accompanying his wife Christine to medical consultations so that he was unable to be involved in the disease and medical management conversations.

"… because of COVID, Christine was having to go to the hospital on her own for appointments and I had to sit in the car park outside or has done telephone consultations which obviously I can't really take part in." (Int18: Donald, cared for his wife)

In another scenario, the lack of involvement in the care process appeared in HCPs' refusal to allow the presence of FC while they were conducting the care visit for PwC. This was the case of George who asked the paid carers to let him attend his wife's care visit to learn from them; however, they refused and forced him to leave.

"And once or twice I asked if I could go in to see what they did, how they got Teresa out of bed… And I got told that I'm not a professional, they were trained to do it but I wanted to see how they lifted her, so as I didn't hurt Teresa, if you know what I mean." (Int19: George cared for his wife)

This made George frustrated about his exclusion from care process and being treated as a stranger to the caregiving relationship, in spite of being responsible for his wife's care all the time outside the visits schedule. This triggered his feelings of inferiority when he perceived that paid carers treated him as less qualified to care for his wife.

“I felt they were trying to treat me as if I was an old idiot and I didn’t know what I was doing.” (Int19: George cared for his wife)

Furthermore, dismissing FCs’ involvement in care made them feel desperate and helpless. This occurred when limits were imposed on their involvement on activities which were necessary to ensure comfortable stay at home for PwC. Although Emily was a mental health nurse, she was not given a permission to administer injectable pain relief to her mother when she had an attack of unbearable pain at night.

“When I rang the hospital and spoke so I have to say a very uncompassionate nurse… I said look can I give my mother some an injection can you just authorize me to do that and she informed me if I did that then I would be struck off as a nurse because… I am a mental health nurse.” (Int08: Emily cared for her mother)

This put Emily in a dilemma between the emotional distress of watching her mother suffering and her caregiving involvement limits which provoked her sense of helplessness and frustration.

“… I can give medication and thought that I couldn’t done that but that was not prescribed it had not been authorized and I was saying but you have got to get some pain killer here I will have got to be able to do something to my mother and it was awful thing to place that dilemma to.” (Int08: Emily cared for her mother)

To conclude, the notion of **“Sharing the journey of caring”** involved two main features of this partnership professional relationship which included checking and contact of FCs and involving them in the care process with proper encouragement and guidance. If this happened,

it enhanced the HCPs-FCs relationships which contributed to their sense of reassurance and emotional relief. However, if FCs experienced exclusion and limited involvement in the care process, a sense of confusion and frustration would be experienced. It was apparent that developing meaningful relationships helped FCs in the study to cope with their caregiving experience. It also minimised their sense of chaos and vulnerability and embraced a sense of reassurance. However, when this did not occur, it increased FCs' struggle and distress.

5.7. Feeling rewarded versus guilt and regret

The interaction between the previously mentioned lived experiences; living in the chaos of caregiving; and interacting with formal support gave rise to the emergence of two major parallel emotional experiences; feeling rewarded versus guilt and regret emotions. These emotional experiences were lived by the FCs throughout the journey of caregiving or beyond. Generally, FCs in the study linked these emotional experiences to certain aspects of their caregiving journey which were either expected or wished when they decided to support PwC at home. These aspects included FCs' ability to manage caregiving chaos, spending quality time with PwC and maintaining the best care and dignified death for them.

5.7.1. Managing caregiving chaos

In this study, it was evident that dealing with caregiving chaos would trigger a cycle of guilt feelings and regret. Conflict experienced while dealing with multiple commitments was the most evident caregiving chaos which was responsible for this experience of guilt and regret. In

other words, FCs realised the difficulties in balancing these competing commitments which made them feel guilty in a way. For instance, Abigail who was working while caring for her father narrated about this conflict which triggered a guilt feeling process.

" Just very, very frustrated and make you feel guilty, like trying to split yourself in two really, trying to look after my own family and work and then, obviously try and care for him as well. Yeah, quite frustrated and upsetting." (Int20: Abigail cared for her father).

These guilt feelings originated from the emotional conflict between the FCs' sense of commitment towards PwC and their work responsibilities. Therefore, they experienced significant frustration and upset which was also echoed in Elizabeth's narratives.

"…I can't get a time off she got no cover and I get tired in on way I am get very frustrated with her (Manager) because I feel like I could do more here I am still have to go to work because I don't like to let people down … " (Int01: Elizabeth cared for her brother)

Whilst other FCs felt backed into a corner when their physical health status limited their ability to provide the care they wished for PwC. The conflict experienced between caregiving commitments and their diminished physical ability created these guilt feelings, emotional torn and the sense of insufficiency in supporting PwC. These were experienced by Doris who had multiple health problems which limited her ability to care for her mother.

"…I wish I could do more, I wish I could do more physically for her but I need help myself at times, so it makes it difficult for me to be able to give her the help

that I would… So I feel guilty that I can't do as much as what I wish." (Int24: Doris cared for her mother)

In some instances, some FCs could not hide their suffering in front of PwC; this increased the intensity of their guilt feelings. This was evident with Stephanie who suffered from severe back pain linked to the caregiving activities. Stephanie could not mask her physical and emotional struggle while she was with her mother which made her felt significantly guilty.

"But it was draining and it was physically draining on my back, I was having to lay down a lot and I was in tears sometimes to my mum and then that probably didn't help her. And I think I feel guilty now, I think God she was dying and I'm in tears to her all the time but that was the relationship we had…" (Int16: Stephanie cared for her mother)

Furthermore, these guilt feelings would be intensified by the uncertain notion of the prognosis. Consequently, FCs would ignore their suffering while caring for PwC to limit these guilt feelings afterwards which was reported by Doris in the following narratives.

"I do feel sometimes when she says things like oh are you coming over today and sometimes I just don't feel well enough to drive. But I will go… And when I get there I'm sort of painting this face of 'Oh I'm fine'… And then I'll get back in the car and I'm exhausted… I can't say no, this is the trouble… especially when you're not sure how much time you've got left with them, you don't want to say no, you want to be able to do things or be there for them. And sometimes that's difficult when I'm dealing with my own sort of conditions and not feeling well myself." (Int24: Doris cared for her mother)

In other situations, the sense of chaos and disturbance induced by the caregiving process would cloud the FCs' thought process and impact their support-seeking behaviour. Then, they felt regret of not being able to advocate for more support to foster their coping with caregiving at home which stated by Marilyn.

"Looking back now, I would certainly have pushed for more support. You know when this is happening you're not really capable of… it's very traumatic, your head's all over the place. I just feel that all that should be done for you, not that you've got to go chasing help." (Int22: Marilyn cared for her husband)

Similarly, other FCs felt regret that they were not aware of their support needs and were not proactive in voicing these needs. For instance, Natalie expressed her regret of not being able to pay attention to her emotional needs during the caregiving journey so that she could have accessed the support she needed earlier.

"The only other thought I had was the counselling I've had after, I wish I'd had it during… I would have considered now paying for my counselling earlier rather than waiting for afterwards…" (Int12: Natalie cared for her husband)

In summary, caregiving chaos was a significant source of guilt and regret feelings. When FCs experienced a significant disturbance which was created by managing the caregiving process and the uncertainty of prognosis, emotional conflict was experienced and resulted in guilt feelings and regret. These feelings were triggered by an inability to maintain the balance between different commitments. On the other hand, regret feelings were evident if FCs missed their opportunity for support either intentionally due to prioritising PwC's support or

because they lacked the awareness of their support needs, and the chaotic context of caregiving muddled their thought process.

5.7.2. Spending quality time

Spending quality time with PwC was a significant driver for FCs to provide care at home. This brought about a sense of reward for several FCs in the study which was narrated by Jennifer about her experience of her husband's care.

"I think the rewarding part was we managed to spend all that time together, which… yes he was very poorly but that was good." (Int07: Jennifer cared for her husband)

The sense of reward was also experienced when the expectations about the privilege of supporting PwC at home was accomplished. This was apparent when the caring dyads were able to spend their time as normally as possible and practise their favourable routines within the limitations of the disease and caregiving. Maria reflected about achieving her wishes of spending pleasant time with her husband while being at home.

"…it was good that we could once the carers and the nurses had gone, we could sit and chat, we could watch movies and just do things that we'd normally done. Something that I thought about and this happened…" (Int11: Maria, cared for her husband)

Furthermore, the COVID pandemic context amplified the sense of reward and achievement which was experienced by FCs who provided the care at home during this difficult time. FCs perceived that caring at home enabled them to spend quality time without experiencing the

visiting limits which became more complicated during the COVID pandemic in case of admission have had occurred. Stephanie reported the privilege and reward of enabling her mother to spend quality time with her family when social gatherings were limited during the pandemic lock down.

" …I think we had to be sensible with COVID. I mean she had to see her sisters … so they were in our bubble and they came. But it was positive as I say in terms of her not being in hospital that they could just come and go, no parking to worry about, no visiting restrictions." (Int16: Stephanie cared for her mother)

On the other hand, some FCs regretted of not being able to spend enough quality time with PwC. Being overwhelmed with caregiving tasks and having limited support with these activities were the significant barriers to spending sufficient quality time with PwC. This was apparent in the situation of Barbara who regretted spending the most of her mother's visits on caregiving duties rather than enjoying precious time with her. She thought that if she has had access to more support, this would have not been a barrier to enjoying a quality time with her mother.

" I would have pushed for more support all along so we could have made the last few months in particular mums like more about spending time together other than worrying about going tomorrow thing or getting the washing on or whose is going on the drugs running down to (Pharmacy) and with those kind of things which really retracted what for us was important… but it would have been more important to have actually had some more quality time for us and I did that is my one regret. " (Int02: Barbara cared for her mother)

Whilst Stephanie identified the difference of spending quality time as an informal care provider for PwC and having quality time as a relative which denoted an identity conflict issue. In this context, Stephanie regretted that she did not enjoy her quality time as a daughter rather than an informal care provider for her mother. Despite these regrets existed, Stephanie acknowledged spending quality time with her mother, but that her enjoyment of this time was limited by the caregiving responsibilities she had.

"I did (get quality time) but no, not as a daughter, as a carer. And that is something that the Hospital nurses did say to me, they were trying to push for mum to go into the hospice. And the nurse did say 'Stephanie, you want to be a daughter not a carer'. And that worried me at the time… Now when I look back, I get a little bit disheartened with that comment from the nurse because actually being the daughter was caring and doing the caring I think but it just unfortunately got to the point where I broke…" (Int16: Stephanie cared for her mother)

Likewise, in Barbara's situation, Stephanie acknowledged that the delayed access to support limited her chance for enjoying personal time with her mother as a daughter and resolved this identity conflict for a bit of time. Therefore, she regretted missing an opportunity for support which would have facilitated this favourable experience to happen.

"…they were so long getting the carers in place and the support in place. But if that had have been straightaway, it would have been a lot different and I'd have maybe felt a bit more like I could be a daughter and just sit there and chat." (Int16: Stephanie cared for her mother)

To sum up, it was apparent that spending quality time with PwC was a precursor for the sense of reward and honour. However, in some instances, this was hindered by the chaotic caregiving context of multiple competing duties combined with the limited formal support. Hence, FCs developed a sense of regret for losing this opportunity of the precious time with PwC.

5.7.3. Maintaining the best care and dignified death

Maintaining the best care and dignified death was another aspect of the FCs' overall experience which contributed to either their feeling rewarded or guilt and regret. When FCs realised that they were able to grant PwC the best care while being at home, this gave them a sense of satisfaction and reward. For instance, Stephanie felt rewarded for being able to provide quality care to her mother at home.

"I feel because she was at home, she got the best care and kind of lived longer really, as much as probably mum didn't want that for her but for us, that was the rewarding part, that we kind of had that bit longer because she was getting the top care…" (Int16: Stephanie cared for her mother)

Whilst the sense of reward for other FCs was experienced through their interpreted meaning ascribed to some caregiving activities. For instance, Natalie talked about her appreciation of the caregiving acts such as personal care tasks that she used to do for her husband. This gave Natalie a pervasive sense of achievement and pleasure through identifying these aspects as a sign of love and a quality marital relationship.

"…those things (clean husband hands) became really important as the carer for me because it felt like I'm his wife and I can do these things for my husband…." (Int12: Natalie cared for her husband)

When FCs realised that they provided the best and compassionate care for PwC, it provided them with a pleasant and comforting lifelong memory which was echoed in Natalie's following dialogue.

"And that's a privilege because that will be our family script, how we recount Albert's dying and his journey, they were with us throughout." (Int12: Natalie cared for her husband)

Moreover, this sense of satisfaction in care provision helped other FCs such as Emily to cope with their grief.

"…it help me grief better knowing that I have done everything I could and have there is nothing else I could have done to care for here…" (Int08: Emily cared for her mother)

The sense of reward and emotional comfort was heightened with the HCPs' acknowledgement of FCs' achievements in the provision of best care and achieving home death. Emily received an acknowledgement letter of her efforts which enabled her mother to stay and die at home as she wished.

"… afterwards she sent a very lovely letter as (a) sort of reflecting that actually my mother she would have been never able to have died at home if it have not been my care… she did acknowledge that it was sort of my emotional care of my siblings and my step-father that had allowed my mother to be died at home

and be cared for her at home which was a lovely thing she did that was a lovely letter to receive." (Int08: Emily; cared for her mother)

Another aspect of the rewarding experience of FCs was apparent in achieving a dignified death at home for PwC as they wished. The notion of dignified death was perceived if PwC was surrounded by the family while dying, and properly being able to say good-bye to them. In such case, FCs felt a great reward and reassurance. In her interview, Stephanie expressed her gratitude for being with her mother at the moment of death and reassuring her which triggered a great sense of emotional comfort and reward. However, Stephanie acknowledged that the presence of HCPs' support facilitated this experience to happen; a night-sitter who called Stephanie to be with her mother during her final moments.

"…it was so rewarding to be able to hold my mum's hand at the time… if it wasn't for that night-sit who knocked on the door, we would have found my mum in the morning and we would have had the children to deal with. And it would have been a whole different ballgame…" (Int16: Stephanie, cared for her mother)

This was also the case with Emily who felt significant success and reward when she was able to achieve her mother's wish to die in her familiar environment at home.

"There were lots of really fantastic positive things from that experience process the family in terms of caring for her having at home in her own bed… we were able to look after in a way she would have wanted." (Int08: Emily cared for her mother at home)

On the other hand, guilt and regret feelings were common experienced by FCs in the study if they realised that a comfortable dignified care and death at home could not be achieved and their ambitions regarding the place of care and dying were not met. Consequently, they would experience a cycle of self-blame, regret, and a sense of failure. This was an assumption of Emily talking about her experience with her mother's and her belief that she would die in severe pain in a one night. Emily presumed that if her mother died on this occasion, she would have been guilty about her decision for caring for her mother at home.

"I did think she was dying that night and she was in such agony and distress. And if she had died that night I'd have never forgiven myself, I would have always blamed myself for taking her out of the hospital… So if she had died that night I would have been forever believing that I had made the wrong decision, I had contributed to her dying in acute excruciating pain and that would have been awful." (Int08: Emily cared for her mother)

On some occasions, FCs realised that caring at home could not be continued due to difficult coping with caregiving and PwC's suffering, therefore, admission to the hospice was perceived as the ultimate way to relieve this suffering and difficult coping. This was reported by Victoria about her husband's admission to the hospice.

"His care was quite intense and you know I was getting tired and my son was the (only) with me… We felt and the doctor my GP felt that he should be at the hospice for the end." (Int05: Victoria cared for husband)

However, other FCs developed a great sense of guilt and failure when admission occurred. In the case of Heather, she significantly struggled in caring for her husband with the limited support she experienced. After several negotiations, her husband Mark agreed to go to the hospice. However, Heather developed intense guilt feelings when Mark went to the hospice, and this was exaggerated when her expectations regarding hospice care were not met during the COVID pandemic. During the COVID pandemic restrictions were placed on hospice visits limited the time spent with her husband and the activities she wished to do such as sharing meals together. Furthermore, Mark got COVID and was isolated which transformed Heather's experience for the worst. Then, Heather developed intense guilt feelings, regret, and frustration because she was an activist for her husband's admission to the hospice.

"And I genuinely, hand on heart, if I'd been told about the conditions at the hospice… I could have kept him at home, and I would have struggled on knowing he'd got so little time left. And at home he was safe, he'd got no COVID… But he goes up there and he gets COVID and he gets the experience that he didn't want, which was to be in a dark dismal quiet place, which it was." (Int10: Heather; cared for a husband)

Meanwhile, Heather felt a failure of not being able to continue caring for her husband at home and he got an undignified death.

"… I don't feel as though I did enough. I felt as though I'd failed him… with him going in the hospice and ending up like that, I felt as though I'd failed him." (Int10: Heather cared for her husband)

Conversely, these guilt and regret feelings would be transformed into a satisfaction if FCs realised that the admission was the best option for PwC's comfort and well-being as well as a relief for FCs. For instance, Marilyn talked about her experience of this emotional transition when she realised that her husband got better and dignified care at the hospice rather than at home.

"… initially the feeling was terribly guilty, overwhelmingly guilty. Annoyed that Andrew had got to go in, I couldn't go with him. I did nothing but cry the whole day. Terrible, terrible feeling. But then they allowed me to go in the evening and I soon realised that he was getting the right care… And so I felt that he was in the right place." (Int22: Marilyn cared for her husband)

However, Marilyn perceived that if adequate support has had been granted at home, she would have coped well with caregiving and her husband would have stayed at home towards the end.

"The thing is with the right kind of help Andrew could probably have stayed at home." (Int22: Marilyn cared for her husband)

To summarise, achieving best care and dignified death for PwC was a desired ambition of the caregiving experience. However, if this was not possible, this would result in a deep long-lasting feeling of failure, regret, and guilt. It was evident from the data that the FCs in the study experienced a transient feeling of reward or guilt and regret throughout their caregiving journey. However, these feelings were more realised afterwards.

For some participants, the negative feelings only constituted a part of their experience besides their pleasant memories. Whilst, for others it overwhelmed their whole caregiving experience and created long-lasting upset and frustrations.

5.8. Chapter Summary

This chapter proposed a theory which interpreted the FCs' experience of EoLC at home through three major theoretical categories which were evolved through the grounded theory analysis. These categories described the FCs' experiences as "**Facing the caregiving chaos while interacting with formal support"**. It also highlighted the nature of the resultant emotional experiences of this major process of **"Facing the chaos"** which formed mixed feelings of reward or guilt and regret. These findings also highlighted the possible role of formal support in the formation of the FCs' long-lasting experiences and their evaluation of caregiving process.

CHAPTER SIX: DISCUSSION

6.1. Chapter introduction

The previous chapter presented the study findings and proposed a theoretical explanation of the experiences of providing EoLC at home for a cross-sectional sample of FCs of PwC. This chapter discusses the presented findings and the proposed theory, considering the wider literature and other relevant theories.

6.2. Facing the caregiving chaos in the light of formal support …. A journey of reward, guilt, and regret

In this study a theory was developed that explained the experiences of FCs of PwC receiving home-based EoLC. FCs' experiences depicted an overall process of "**Facing the caregiving chaos in the light of formal support … A journey of reward, guilt, and regret"**. This process illustrated that FCs moved throughout different contextual layers of caregiving experience that was characterised by chaos. Living in the chaos of caregiving was the essence of FCs' EoL caregiving experiences. It involved experiencing and coping with various aspects of the chaotic context of caregiving, such as the shock of unexpected diagnosis and prognosis and being new to family caregiving. While coping with this chaotic context, FCs engaged in a process of interaction with formal support that constituted another layer of their chaotic caregiving journey that either minimised or contributed to the experiences of chaos. Feeling rewarded versus guilt and regret was the third major emotional experience that was embedded in the chaotic context of caregiving while interacting with formal support. In such

emotional experience, reward feelings could characterise most of the caregiving journey or it could intertwine with guilt and regret emotions which portrayed the chaotic emotional experience of cancer caregiving at the EoL.

In other words, the experiences of FCs in the study described three interrelated social processes of cancer caregiving at EoL, which included living in the chaos of caregiving, interacting with formal support, and feeling rewarded versus guilt and regret. Cancer caregiving at EoL constructed an emergent life transition that created stress, confusion, uncertainty, and chaos. However, in response to this chaos, FCs worked to adapt to their new role and life transition through their own ways of coping, such as creating a new normal and learning about caregiving, to cope with the new obligations and ameliorate the associated distress and uncertainty. FCs' interactions with formal support facilitated their coping and minimised their sense of chaos if it established a context of reassurance through the provision of proper support at the proper time and meaningful relationships with FCs were established. However, if this was not the case, FCs' sense of confusion and vulnerability was triggered.

Dealing with caregiving chaos through self-coping mechanisms and support from HCPs led to an emotional experience of reward or guilt and regret. A rewarding experience was triggered if FCs were able to achieve their perceived role gains, such as managing the chaotic caregiving process, having quality time with PwC, and achieving the best care and dignified death for them. While guilt and regret would be prominent if FCs

lost any of these role gains, this could happen as a result of living in a heightened state of chaos and distress combined with a sense of vulnerability and confusion due to improper formal support. In conclusion, if FCs experienced a safe caregiving environment in terms of their enhanced ability to cope and the availability of quality supportive services and caring HCPs, it would help them achieve self-actualisation aspirations in the caregiving journey in terms of a sense of reward and role accomplishment.

These theoretical explanations echoes concepts and interpretations of other caregiving theoretical models, namely the Stress Process model (Pearlin et al., 1990), the Transactional Theory of Stress and Coping (Lazarus, 1984), the Life Transition theory (Selder, 1989), and the Transitions Theory (Meleis et al., 2000). Moreover, this theory expanded our understanding of these models, which will be clarified in the upcoming sections. For instance, The present theory identified caring dyad's relationship as a contextual factor that contributed to chaotic experiences which supports the Stress Process model (Pearlin et al., 1990). However, this theory added that PwC's response to illness was a potential trigger for changing relationships. The present theory also provided a clarification of the coping process in Stress Process model (Pearlin et al., 1990) and the Transactional Theory of Stress and Coping (Lazarus, 1984) regarding how it was practised by cancer FCs at EoL (e.g., learning about caregiving, sharing the caregiving) and the possible impacts of coping process (i.e., minimise/increase the experienced chaos). This theory also highlighted the link between informal network

support (i.e., family and network domain of caregiving context dimension in the Stress Process model (Pearlin et al., 1990) and the development of positive rewarding experiences. This was achieved through facilitating managing caregiving chaos and spending quality time and not only minimised the caregiving induced stress. Furthermore, this theory provided clarification on how informal network support was practised among FCs' wider family. This theory indicated that caregiving as a transitional event could involve a process of self-learning which supports other theories of transitions e.g., Life Transition theory (Selder, 1989), and the Transitions Theory (Meleis et al., 2000). However, the present theory added that this process of self-learning in EoL caregiving in cancer could be challenging for some individuals experiencing rapid deteriorations that increased their juggling and chaos.

The present theoretical interpretations expanded the understanding of how the social support as a mediating factor in Stress Process model (Pearlin et al., 1990) would increase or minimise the sense of chaos and contribute to a positive rewarding experience. This was achieved through a discussion of qualities of formal support interactions with FCs. Moreover, The present theoretical interpretation added further credibility to some aspects of Martz and Morse (2017) theoretical model **"The changing nature of guilt in family caregiving"** that described the FCs experiences of guilt throughout care transition when a dying parent couldn't stay at home until EoL. For instance, **"Breaking Down"** core category of Martz and Morse (2017) described the initial FCs' feeling of guilt due to increasing caring needs and diminished FCs' ability to

continue caring at home with conflicting responsibilities. This mirrors the present study sub-categories of **"Managing caregiving chaos"** and **"Maintaining best care and dignified death"** that explored some aspects of guilt construct in the caregiving process. These subcategories identified some guilt incidence conditions such as, roles insufficiency and conflict mentioned in Section 5.7.1 and the sense of failure when admission occurred as highlighted in Section 5.7.3. This addressed Martz and Morse (2017) recommendations for further exploration of the guilt construct and its resolution in FCs. Lastly, this theory provided an explanatory argument of how rewarding experiences could be achieved at EoL which echoes other conceptual framework of positive aspects of caregiving (Carbonneau et al., 2010). Moreover, this theory expanded our understanding of the potential role of formal support in enabling these positive experiences to happen.

In the following sections, the properties, and relationships of the three major categories of the present theory "**Facing the caregiving chaos in the light of formal support … A journey of reward, guilt, and regret"** will be discussed in relation to the existing literature and theories.

6.2.1. Living in the chaos of caregiving

Meleis et al. (2000) argued that experiencing health and illness changes initiates a transition process which would have detrimental impact on individuals' quality of life and coping. Similarly, Selder (1989) argued that a life transition is triggered if the existing reality was disrupted as a result of life events. FCs started their chaotic journey with the unexpected diagnosis of cancer and the distinct trajectory of the illness progression. Cancer was not ultimately a disease which was expected by FCs when PwC suffered from simple symptoms such as, shoulder pain or earaches. Since, cancer is not a part of normal expectations of family life which has implications on the present and future goals and priorities (Little et al., 2022, Kristjanson and Aoun, 2004). Therefore, when FCs received the diagnosis, it was experienced as a shock that has disrupted their plans and life routines. This is because the term **"Cancer"** is more often associated with dying so that confirming the diagnosis provoked a sense of threatened loss of PwC and future aspirations which were now deemed impossible (Wilkinson and Lynn, 2005, Little et al., 2022).

Another aspect of the chaotic journey of FCs in the study was the unexpected disease trajectory and deterioration. Although the cancer trajectory has a predictable gradual pathway (Wilkinson and Lynn, 2005, Comstock Barker and Scherer, 2017), most of the FCs in the study described it as unexpected trajectory which heightened their sense of life disruption. It seemed that each deterioration was perceived as a minor life transition within the major transition of cancer caregiving which

necessitated manipulating existing routines for accommodating to any change in the prognosis (Selder, 1989).

In their mixed methods study to define illness trajectory of breast cancer, Reed and Corner (2015) argued that cancer passes through a defined five trajectory phases that included a pre-trajectory phase in which the onset of symptoms starts, a trajectory phase when diagnosis is confirmed and support seeking and treatment started, living with progressive disease phase which involves dealing with burden of disease complaints, fluctuated active treatment, recovery and illness, a downward and dying phase which involves increased deterioration and acute episodes while looking for EoLC rather than an active treatment. Whilst Strauss (1984) alluded that chronic illness trajectory is usually uncertain so that expectations could be unpredictable. This interpreted the state of uncertainty and chaos which were experienced by FCs in this study especially for those who cared for PwC with significantly rapid cancer progression, like pancreatic cancer. A clinical review by Murray et al. (2005) contended that although cancer trajectory involves a predictable progression which might be extends over months or years, individuals would vary in terms of the rate of progression and dying phase (Taylor and Pagliari, 2018). This suggests the importance of a regular review of prognosis, updating PwC and their FCs with relevant information and adapting the support accordingly (Murray et al., 2005, Taylor and Pagliari, 2018).

Transition into cancer caregiving role at EoL is characterised by changes in roles, responsibilities, and priorities (Meleis et al., 2000). In

the present study, most FCs found that the uncertain nature of illness altered their priorities and roles such as parenting and work that overlapped with caregiving. This was mirrored in a study by Olson and Connor (2015) who explored the emotional experiences' variations of carers of cancer patient. Roles' conflict increased FCs' sense of anxiety, distress, and guilt if they failed to achieve the balance between these competing commitments (Duggleby et al., 2017, Uceda-Torres et al., 2016, Brazil et al., 2010). Feelings of guilt could emerge from the perceived role insufficiency in any aspects of their responsibilities, such as delivering the care, working, or parenting. Changes in FCs priorities due to their role transition made some FCs in this study encountered a self-care versus PwC's care dilemma especially if they suffered from their health problems. This increased their sense of distress since, they had to choose between their wellbeing or providing the care as they wished which would result in burden and suffering. The lack of acknowledgement of FCs' own needs and well-being was evident in other studies (Uceda-Torres et al., 2016, Yang et al., 2021). For instance, Miranda do Vale et al. (2019) who explored FCs' self-care needs in the palliative home care context found that priority was attributed to caregiving which limited FCs' attention to their self-care needs. This highlights the importance of HCPs' guidance to FCs about the necessity of their self-care and well-being.

In their Stress Process model, Pearlin et al. (1990) identified that caring dyad's relationship is a contextual factor that could impact the caregiving process and linked it to the stress experience. The present findings revealed that PwC's response to illness and their relationship

with FCs contributed to either increased or decreased the sense of chaos and disruption. Strained relationships were attributed to the way that PwC projected their response to their illness. In some instances, this was interpreted by FCs as a lack of appreciation of their efforts leading to further frustration. Similarly, Stajduhar et al. (2008) who qualitatively explored the factors influencing FCs' coping, reported that disease sometimes negatively affects the quality of relationships between patients and FCs where it becomes stressful and draining. They explained this by the link between the FCs' coping and PwC's perspectives and responses to illness (Stajduhar et al., 2008). However, the present study noted that if PwC held a positive perspective towards their illness, this facilitated FCs' ability to cope with caregiving. Similarly, Li and Loke (2013) in their critical review about positive aspects of caregiving reported that PwC's optimism influences FCs' ability to cope. Thus, the well-being of patient and FCs are intertwined, and the quality of their relationship affects caregiving coping (Lim and Zebrack, 2004, Stajduhar et al., 2008, Kim and Baek, 2022).

Transitions theory (Meleis et al., 2000) indicated that preparation is an important factor for successful role transition. However, in this study lack of caregiving preparedness triggered the sense of chaos and confusion. Similarly, in their systematic review of FCs' needs while providing home- based palliative and EoLC to PwC, Bee et al. (2009) identified that unpreparedness alters FCs' confidence to perform practical caregiving tasks. This leads to a heightened level of uncertainty and chaos and the feeling of role insufficiency especially with progression

towards EoL (Stajduhar et al., 2008, Bee et al., 2009, Mason and Hodgkin, 2019, Wahid et al., 2018).This role insufficiency and distress increased with the complexity of practical tasks which required professional education for preparation, such as symptom management and patient manual handling due to their impact on patient comfort and the serious consequences of the improper practice (Bee et al., 2009, Tolbert et al., 2018). Emotional preparation was also essential for dealing with some caregiving tasks which would have an emotional component to lessen the experienced distress and apprehension (Bee et al., 2009, McDonald et al., 2016, Tolbert et al., 2018, Bilgin and Ozdemir, 2022). In this study, some FCs lacked this preparation, which increased their emotional distress. This was attributed to the unrealistic expectations about caregiving tasks so that emotional shock was evident due to inability to contain the physical and emotional aspects of these tasks.

Family carers' preparation through practical and information sessions is necessary to relieve their confusion and distress and enhance their sense of confidence (Bee et al., 2009, Harding et al., 2012, Mason and Hodgkin, 2019). On the other hand, this study noted that prognostic uncertainty and rapid deterioration required prompt preparation and rapid caregiving training to cope with the swift decline. The present study found that caregiving preparation through a formal healthcare job training or previous caregiving experience gave some FCs the confidence to manage caregiving at home which reduced their vulnerability and distress (Maddalena et al., 2010, Santerre-Theil et al., 2022). Thus, FCs' assessment should address the existing caregiving

skills to foster FCs' involvement and target their specific caregiving learning needs (Docherty et al., 2008).

Facing the caregiving chaos involved varied attempts to regain equilibrium and maintain control over the disruption caused by the caregiving situation. Pearlin et al. (1990) identified coping as a mediator for the caregiving stress process in their theoretical model. Coping is described by Pearlin et al. (1990) as acts and efforts that are done by individuals on their own behalf. The process of coping with caregiving chaos also comes in line with the Stress and Coping theory of Lazarus (1984). According to the Stress and Coping theory, individuals (FCs in this study context) engage in a continuous process of appraisal and response to an environmental stimulus (chaotic caregiving context), which disturbed FCs' status quo. Then, individuals (FCs) involved in a process of adaptation to regain balance and develop some sense of mastery (Lazarus, 1984). However, this process of coping was influenced by FCs' personal characteristics to some extent in this study. For instance, FCs' self-efficacy and advocacy skills were evident as facilitators for coping with caregiving chaos which is mirrored in other studies (Stajduhar et al., 2008, Holm et al., 2015). This could explain the variations in FCs coping ways and the differentiation of their support needs to empower their ability to cope. Meleis et al. (2000) and Selder (1989) argued that when FCs face a caregiving transition, they involved in a process of **"Engagement"** with the transitional event (caregiving) to cope with its consequences through looking for information, preparation, and activity adaptation. However, Lazarus (1984) classified coping

mechanisms with stressful event (caregiving) into problem-focused and emotion-focused coping. The first refers to actions to mitigate the perpetrators of caregiving stress, whereas emotion-focused coping involved managing the feelings associated with the chaotic caregiving experience (Lazarus, 1984). In this study, FCs used a mixture of the two coping dimensions such as creating a new normal, sharing the caregiving and learning about caregiving as a problem-focused coping, and they tried to be resilient and thinking rationally and positively which could be considered as an emotion-focused coping strategy.

Creating a new normal was a coping mechanism adopted by FCs in this study to deal with the chaos triggered by PwC's illness and associated caregiving responsibilities and this is supported by other studies (Milberg and Strang, 2004, Duggleby et al., 2010, Penrod et al., 2012, Fennell et al., 2017, Etkind et al., 2019). However, this new normal varied among FCs in this study which had further implications on their existing routines. Lazarus (1991) identified two influencers of the coping process: individual factors such as, beliefs, values and goals, and contextual factors such as, environmental demands and available resources. In this study, the nature of illness progression, FCs' perspective and appraisal of the caregiving process, their personal goals and values, and their existing roles and new responsibilities and demands could explain the FCs' response's variations and the differed ways they created their new normal (Cooper and Quick, 2017). For instance, many FCs dealt with the caregiving as the prime commitment which resulted in giving up other roles such as, work, study, and parental

roles. This was rationalized by the perception that caregiving was more important, urgent, and temporary. However, the process of creating new normal did not necessarily involve putting other aspects of life on hold if caregiving was minimal and could be managed along with other roles. Therefore, other FCs found a benefit of keeping old routines along with emerging caregiving commitments during early stages of caregiving role for achieving a sense of normality. Whilst others viewed and dealt with caregiving as a further burden that was added to their other responsibilities especially when caregiving became intense with increased support demands. Then, the new normal might induce further chaos and possible feelings of guilt and regret, especially if role insufficiency was perceived in any aspect of the previously existed roles or in the new caregiving roles and responsibilities (Duggleby et al., 2017).

Being resilient and thinking rationally and positively appeared as a coping way with caregiving chaos for some FCs in this study. This would be linked to FCs' personal traits and life experiences which prepared them to deal with the distress imposed by the caregiving chaos. This supports the notion of **"Caregiving manageability"**, which was reported by Milberg and Strang (2004) who explored the concept of manageability in palliative home care. The authors attributed FCs' ability to positively manage their situation to their sense of confidence in their coping abilities. Meanwhile, resilience and optimism enabled FCs in this study to adapt their thinking and attitude in a positive way to cope with caregiving chaos (Stajduhar et al., 2008, Palacio G et al., 2020).This could interpret the reason why some FCs considered caregiving

challenges as a non-separable part of their experience, which they should deal with and overcome. This echoes the **"Just-do-it"** approach of participants in Stajduhar et al (2008) study which helped them to cope.

Resilience also appeared in this study in FCs' adherence to leisure and well-being practices such as, physical activity as a way for stress reduction and relief. Similarly, in their qualitative investigation about the caregiving experiences of FCs of persons with advanced cancer in Singapore, Leow and Chan (2017) found that participating in leisure activities helped FCs to distract their mind and cope with negative emotions associated with caregiving process. The present study also revealed that logical thinking and weighing risks and benefits helped FCs in caregiving decision making process especially during the COVID pandemic disruption. In similar context, participants in Nyblom et al. (2022) study reported using this coping strategy to find innovative solutions to caregiving-related problems.

Informal support networks were identified as both contextual factor for the caregiving process and as a mediator that either facilitates or hinders the process of caregiving (Pearlin et al., 1990). In this study, sharing the caregiving among family members was another way of coping with caregiving chaos. It had a significant positive impact on FCs' manageability and relief of their sense of disruption. The present findings found that informal support minimised FCs' juggling between multiple commitments and enabled spending quality time with PwC. Informal support empowered FCs in this study through help with hands-on care, household tasks and provision of emotional support which triggered a

sense of reassurance (Milberg and Strang, 2004, Strang and Koop, 2003, Stajduhar et al., 2008, Brazil et al., 2010, Johnston et al., 2012, Guo et al., 2021, Bouchard et al., 2023). This sense of reassurance echoes the **"Feeling connected"** construct in Transitions theory (Meleis et al., 2000), which was considered a process indicator for the successful role transition and minimised sense of chaos.

Informal network support appeared throughout this study in two forms. Minimal or partial support which involved intermittent and occasional help with practical tasks or support with the emotional aspect of caregiving through sharing of emotions and supportive communication. The other form of informal support was the complete sharing of caregiving through an organized scheduled system of responsibilities. This revealed the variations in families' responses to crises or transitional events such as, cancer caregiving at EoL which offered further insight into the varied dynamics of informal network support in caregiving process that could be warranted for future research.

On the other hand, this study revealed that lack of informal support created distress and family conflicts (Martín et al., 2016). This was attributed to unfulfilled expectations of support from people who had a relational commitment to PwC which were also reported in two earlier studies (Brazil et al., 2010, Stajduhar et al., 2008). On some occasion, it could be attributed to the limited consideration of the caregiving toll on behalf of the other family members (Stajduhar et al., 2008, Murrell et al., 2023), which was apparent in one caregiving situation in this study. However, caregiving context could influence the ability of the informal

network to contribute to the caregiving processes. This was evident during the COVID pandemic when lockdown and restrictions limited the availability of in-person help from the informal network. Consequently, this triggered a sense of frustration and social isolation for FCs who received palliative care at home during this unprecedented time (Nyblom et al., 2022).

Engagement in the self-learning process was other way to face the chaos associated with transition into cancer caregiving at EoL. FCs in this study tried to seek caregiving knowledge to overcome the uncertainty associated with their life transition to EoL cancer caregiving (Selder, 1989). This could be a way to build FCs' capacity in the **"Creating a new normal"** process which was discussed earlier (Duggleby et al., 2017). Furthermore, the findings illustrated that FCs tried to contain their sense of role insufficiency through this process of self-learning about cancer disease and associated caregiving practices. In some instances, self-learning was achieved through experimentation and trial and error approach. However, it elicited risks to PwC in case of improper caregiving practices.

Other theories such as the Life Transition theory (Selder, 1989), and the Transitions Theory (Meleis et al., 2000) also highlighted that the process of information seeking formed an essential part of the coping and engagement process with a life transition event. However, caregiving was experienced by FCs in this study as a learning curve in which they needed to incorporate a large amount of information in a short time (Pope et al., 2018). Thus, the process of self-learning could be ineffective in the

context of EoL caregiving with rapid illness trajectory, multiple commitments and complex support needs that required hands-on training on sophisticated practical tasks. Although the findings of this study agrees with Selder's (1989) theoretical position, the present findings suggested that this might not be applicable to some FCs who were caring for PwC having rapid deteriorating and complex needs with limited FCs' time for self-learning.

In summary, the first category of the present theory identified the properties of the chaotic cancer caregiving experience at EoL. It also described how the FCs coped with the disruption triggered by the disease and caregiving role transition. Although the findings support various theoretical frameworks in the caregiving process, it expanded our understanding of the complex nature of caregiving chaos at EoL which was compounded by the contextual transition of the COVID pandemic. It highlighted the varied nature of coping with the caregiving chaos, which changed depending on FCs' personal and contextual factors and the family's orientation to the caregiving process. This further added to the existing literature of caregiving stress process and coping. The following section introduces the second theoretical category that discusses the FCs' experiences of interaction with formal support.

6.2.2. Interacting with formal support

Formal support is considered an important aspect of FCs' coping with caregiving experience (Andershed and Ternestedt, 1998, Stajduhar et al., 2008, Linderholm and Friedrichsen, 2010, Martín et al., 2016, Molassiotis and Wang, 2022). When FCs started their caregiving journey,

they experienced a process of interaction with formal support and HCPs that shaped their overall caregiving experience. The Stress Process model (Pearlin et al., 1990) identified the availability of formal support as one of the contextual factors that influence the caregiving process. However, the quality and extent of the support provided by this system is a mediating factor for increasing or minimising the impact of the caregiving stressors (Pearlin et al., 1990). The present theoretical interpretation in this study provided an explanatory argument about how this process occurred in the context of EoL caregiving. The findings highlighted that creating a context of reassurance might reduce the impact of caregiving chaos which could be achieved through the provision of reliable formal support. In contrast, failure to provide optimum formal support was contributed to a sense of vulnerability and confusion and significant emotional distress which echoes other studies (Brazil et al., 2010, Seal et al., 2015, Barlund et al., 2021, Molassiotis and Wang, 2022). Building the context of reassurance in this study involved two broad aspects: the provision of proper support at the proper time (Robinson et al., 2017, Barlund et al., 2021) and having a meaningful relationship with HCPs (Molassiotis and Wang, 2022). In this study, getting the proper support at the proper time characterised by three features: receiving individualised support, ease of access to support and timeliness of support.

Individualised support was achieved if this support was organized around PwC and FCs' needs, preferences, and routines. If this happened, it would facilitate the **"Creating a new normal"** process. In

other words, when support was planned and provided considering the caring dyad's routines, it helped FCs to adapt to the new constructed reality of caregiving which in turn could minimise the effect of caregiving chaos. Furthermore, the provision of individualised support could contribute to an emotionally secured atmosphere for enjoying quality time with PwC and maintaining the sense of normality as discussed earlier (Holmberg, 2006b, Klarare et al., 2017, Kmetec et al., 2022). Caring dyads experienced varied support needs that would change with disease deteriorations. This would be compounded with an experienced discrepancy between the caring dyad's routines and support expectations and the way in which the formal support was organised. Then, a sense of individualised support appeared to be lacking. This was apparent in multiple caregiving situations where support visits were not planned and were not congruent with the caring dyad's daily routines and needs. This resulted in distress and on some occasions, the FCs declined the support offered. Similarly, the lack of individualised support was evident in other studies which could reflect the rigidity of the formal support system (Funk et al., 2009, BrobÄCk and BerterÖ, 2003, Shan et al., 2018, Kmetec et al., 2022). This led to a perception that the system ignored the person centred approach to care; where the support system works for people, to prioritise how the system was organised (Funk et al., 2009, BrobÄCk and BerterÖ, 2003, Shan et al., 2018). Similarly, other authors noted that inadequacy of support increased the FCs' burden and exhaustion while dealing with complex caregiving tasks (Grbich et al., 2001, Bee et al., 2009, Brazil et al., 2010, Wahid et al., 2018, Wan et al.,

2022). Therefore, this study argues that the notions of person-centred care and individualised support are important which could be achieved through personalised, skilful, and periodic needs assessment of the caring dyad to ensure that right kind and amount of support is provided (Hauser and Kramer, 2004, Cheng et al., 2022, Marco et al., 2022). The findings noted that the initial meeting and discussion with the caring dyad prior professional support allocation was a helpful strategy to set support expectations and discuss family concerns. This was beneficial for support adaptation according to the caring dyad's needs and preferences.

Ease of access to support was the second element that could facilitate getting the proper support at the proper time which embraced a sense of reassurance in this study. However, it was evident that many FCs experienced difficulty support access for various reasons and felt they were constantly chasing for help which increased their distress and emotional insecurity (Funk et al., 2009, Barlund et al., 2021). Access to support was influenced by three aspects that included HCPs' competence, negotiating the bureaucracy of support access and the impact of COVID pandemic on support access.

This study found that cancer and palliative care knowledge and competence were perceived as important quality of HCPs who provided the care for PwC at EoL. This would facilitate a precise needs assessment, identifying current and anticipatory support needs and on-time referral for support. This echoes participants' experiences in Richards et al. (2011) qualitative study who investigated the experiences

of people with advanced cancer and/or their FCs regarding the out-of-hours care. Hence, HCPs' palliative care experience could facilitate an accurate prognostication and anticipation of potential health problems and provide the proper support (Wahid et al., 2018). This contributed to the FCs' sense of reassurance, mastery and caregiving manageability (Milberg and Strang, 2004, Funk et al., 2009, Wennman et al., 2020, Barlund et al., 2021). However, the incompetent judgment of support needs due to limited palliative care expertise obscured support access and resulted in significant FCs' distress while chasing for the support. This would result in a negative experience, suffering and mistrust in the healthcare system (Funk et al., 2009, Barlund et al., 2021).

Negotiating the bureaucracy for support access was mostly experienced as a barrier for getting proper support at the proper time in this study which mirrors other studies (Richards et al., 2011, Bijnsdorp et al., 2022). For instance, lengthy procedures for accessing support were distressing to FCs who used the **"Single point of access"**. Since, they had to reiterate the same PwC's information every time they used the services. This was frustrating for some FCs who were in urgent need for support. This echoes participants' narratives in Richards et al. (2011) study about the experiences of out of hours services. The authors in this study linked the lengthy process of access out-of-hours care to the lack of continuity care and information. FCs in Richards et al. (2011) study felt vulnerable and distressed of repeating same information such as patient related information and concerns every time they call. Although this information seemed reasonable to legitimize the call, it was perceived

delaying access to support. Another aspect of negotiating the bureaucracy process involved dealing with geographical variations in service provision. This compounded by the limited coordination and communication between services and HCPs which made support access challenging. This heightened the FCs' sense of confusion and distress while complementing the gaps in communication and coordination through transferring information. Similarly, problems in care coordination and HCPs' communication were noted by several studies which hindered timely support access and care continuity (Bee et al., 2009, Brazil et al., 2010, Epiphaniou et al., 2012, Robinson et al., 2017, Wahid et al., 2018, Oosterveld-Vlug et al., 2019). For instance, Oosterveld-Vlug et al. (2019) argued that when several services involved in the care process, there would be improper transfer of information which could lead to missing certain aspects of care. Consequently, this contributed to the FCs' sense of vulnerability, emotional distress, and loneliness (Totman et al., 2015, Shan et al., 2018). This was attributed to the increased level of responsibility on FCs to coordinate different services for PwC. Totman et al. (2015) described this challenge in their qualitative study about the FCs' emotional challenges at home and their experience of HCPs as **"Being the linchpin"** to the care of PwC which made FCs in their study felt frustrated and lonely in their caregiving responsibility. By contrast , the present study highlighted that if HCPs were more proactive in care coordination, this triggered a sense of reassurance and emotional security (Holmberg, 2006a, Barlund et al., 2021, Molassiotis and Wang, 2022) through minimising the sense of responsibility burden in

coordinating the care (Totman et al., 2015, Wennman et al., 2020). This suggests the importance of FCs being assisted in navigating the healthcare system and support (Nielsen et al., 2013, Adejoh et al., 2021) which will be addressed in detail in the practice implications Section 7.4.2.

Negotiating the bureaucratic process of support was linked in the present findings to the availability notion of the formal support. Availability of qualified support and HCPs would guarantee access to the support whenever needed. This was the case of some FCs in this study which triggered their sense of reassurance and confidence in managing caregiving at home which was demonstrated in wider literature (Wennman-Larsen and Tishelman, 2002, Milberg and Strang, 2004, Stajduhar et al., 2008, Funk et al., 2009, Uceda-Torres et al., 2016, Klarare et al., 2017, Røen et al., 2018, Opsomer et al., 2019, Wennman et al., 2020). Røen et al. (2018) qualitatively investigated the factors that promote FCs' resilience, depending on the FCs' experiences and preferences with HCPs' support. The authors in this study found that FCs felt secure when they perceived that they could access HCPs and support anytime they needed. This was opposite to the increased chaos and vulnerability when some FCs in the current study experienced limited availability of support services which led to their feeling with helplessness and emotional distress (Molassiotis and Wang, 2022). It could be argued that limited availability would be linked to staff shortages which imposed limits on the scale and coverage of support system and in turn the accessibility to qualified support (Brazil et al., 2010, Avati et al., 2018,

Bijnsdorp et al., 2022). This highlights the importance of investing in support system human resources to increase formal support coverage and availability of qualified HCPs. A recent House of Commons report (Garratt et al., 2023) about NHS work force in England raised a concern about the number of HCPs which is not congruent with patients' needs that could risk the patients' safety due to the impact on services' delivery. Although the UK government's efforts to increase HCPs' recruitment, certain challenges would limit NHS work force retention such as work-induced stress, burn out, bullying and low pay rate. However, the UK government movement towards international recruitment of HCPs might help in reducing this gap (Garratt et al., 2023).

Telehealth and the use of digital technology in provision of support could be argued a possible strategy to provide instant availability of support (Steindal et al., 2020); however, it requires digital literacy of HCPs and caring dyad (Steindal et al., 2020). A mixed methods study explored the perceptions of FCs and palliative cancer patients of home telehealth, many participants reported the ease of access to HCPs which increased their sense of reassurance; however, participants identified concern over the services integration between telehealth services and normal services (Stern et al., 2012). Furthermore, some participants in this study reported equipment issues regarding the portability inconvenience and technical problems. Similarly, a recent scoping review explored the experiences of home palliative patients' regarding telehealth and reported its beneficial impact on symptom assessment and management as well as fostering the sense of security at home

(Steindal et al., 2020). Therefore, telehealth could complement the standard formal services; however, it could not replace the in-person support interactions.

In the present study interviews were all conducted during the COVID pandemic and the most of FCs' experiences were impacted by this worldwide crisis. The COVID pandemic had a significant impact on support access experiences. This appeared in the mode of service delivery from in-person to remote consultations, frequent cancellation of visits due to staff sickness and closure of well-being centres that offer advice and support. This limited support accessibility during the pandemic lead to a sense of confusion, emotional distress, and vulnerability. These findings reflect those of Fisher et al. (2021) who examined the impact of the pandemic on the adult child caregivers' experiences caring for a parent with a haematological cancer. The authors acknowledged the negative impact of the pandemic in limiting the in-person support due to the appointment cancellations. This in turn led to the exacerbation of existing uncertainty and FCs' distress (Fisher et al., 2021).

In contrast, the Swedish study of Nyblom et al. (2022) reported a normal access to formal support throughout the pandemic which elicited an emotional security for FCs during this unprecedented time (Nyblom et al., 2022). These differences in the experiences of support access during the pandemic might be attributed to country specific policies and regulations in dealing with the pandemic, the rate of COVID infections and the increased pressures on the healthcare system. This highlights

the need for enhanced proactive healthcare planning for potential crises and developing mitigating strategies to minimise the negative impacts on the formal support system (Nyblom et al., 2022). However, this is affected by the availability of system's resources that was originally limited with regards to the working force as highlighted earlier in this section. Santin et al. (2022) explored cancer FCs' experiences and needs as a result of the pandemic in a mixed methods study. They recommended the expanded use of digital technology for FCs support and counselling as mentioned previously in this section. However, those FCs who are uncomfortable with this option could benefit from other options such as telephone support which is more resource intensive option (Santin et al., 2022). This illustrates the potential role of voluntary sector in providing FCs' support in form of volunteer's home help and assistance (Santin et al., 2022).

Getting timely support was an essential element in FCs' sense of reassurance and emotional security in the present study which confirmed the findings of other studies (Funk et al., 2009, Klarare et al., 2017, Wennman et al., 2020). However, the current findings showed that various episodes of delayed support triggered FCs' sense of chaos and vulnerability. This delay was apparent in several situations, such as information provision, equipment allocation and removal, organisation of support package following discharge home, and response to the symptoms' exacerbation. For instance, delayed information provision increased the FCs' sense of uncertainty and distress due to the perceived insufficiency and unpreparedness for caregiving role. A similar

problem was reported in other studies where a delay of information provision was noted as a problem that led to the experienced difficulty in executing caregiving tasks and a sense of emotional insecurity (Bee et al., 2009, Barlund et al., 2021). This highlights the importance of HCPs' proactivity in information provision to prepare FCs and establish their caregiving expectations which could minimise the experienced chaos and uncertainty (Duggleby et al., 2017). Meanwhile, delays in the arrangement of support packages increased FCs struggle with the increasing support demands of PwC. In some instances, this occurred due to the unplanned home discharge without the adequate preparation for the transition to home.

Similarly, in a qualitative study exploring the bereaved relatives of patient with haematological cancer regarding the preferred place of death and care, some participants alluded that delayed planning for home discharge with limited chance of arranging support packages was reported as problematic and limited opportunity of being cared for at home (McCaughan et al., 2019). However, prognostic uncertainty and unexpected deteriorations was thought to be a barrier for achieving this (McCaughan et al., 2019). This highlights the importance of early EoL discussions and planning regarding the place of care and death to provide support package at optimum time. Symptom management delays were experienced in many caregiving situations in this study which made FCs frustrated and distressed while urgent help and proactive support was needed which mirrors the findings of several studies (Funk et al., 2009, Richards et al., 2011, Molassiotis and Wang,

2022) However, this was attributed on some occasions to staff shortages especially in the light of healthcare system pressures during the COVID pandemic which was addressed earlier in this section.

Pearlin et al. (1990) identified social support as mediating factor for caregiving stress which involved two pillars of support: the provision of instrumental support through help with caregiving tasks, and the expressive support through caring relationships. The present theoretical interpretation revealed that engaging in a meaningful relationship with HCPs was important for the FCs' sense of reassurance and counteracted the sense of chaos associated caregiving experience. A grounded theory study explored the FCs experiences of caring for a person with malignant brain tumour (Arber et al., 2013). The authors identified that having helpful relationships with HCPs was important in the process of **"Connecting on the caring journey"** that described the FCs ways for getting the support that satisfy their needs (Arber et al., 2013). In the current study, the process of engaging in meaningful relationships with HCPs included three pre-requisites to establish this sort of relationship which involved HCPs showing compassion and establishing rapport, HCPs engaging in open communication, and HCPs sharing the journey of caring with FCs.

Although, compassionate caring relationship was reported as one of the essential elements of high-quality palliative care at home (Oosterveld-Vlug et al., 2019); this study found that non-compassionate care was experienced in several instances of support interactions. For instance, the limited engagement of PwC in the care process and not

displaying interest in them, thus losing the person-centred-ethos of care were evident in this study. When this occurred, it strained the HCPs-PwC's relationships and frustrated FCs which mirrors other studies (Strang and Koop, 2003, Brazil et al., 2010, Uceda-Torres et al., 2016, Arber et al., 2013). This led to the refusal of support on some occasions which meant that more caregiving responsibilities were devolved to FCs, thus increasing the caregiving chaos and emotional distress. In contrast, in their qualitative study about the emotional work of healthcare assistants in community palliative care settings, Lovatt et al. (2015) reported that the delivery of compassionated care through engagement in everyday life conversations with the PwC while performing the care enhanced the support relationships and established rapport.

This study noted that receiving care from different HCPs represented a barrier to developing rapport with the caring dyads and contributed to increased sense of chaos, confusion, and vulnerability. This supports Klarare et al. (2017) findings which indicated that caring relationships needed time to develop through dealing with familiar staff which was considered an essential aspect of emotional reassurance experience in palliative home care. This study revealed that lack of compassion was also experienced in the HCPs-FCs part of the relationship. The lack of situational sensitivity and superior attitude of some HCPs led to FCs' upset and frustration. The present findings support those of Milberg and Strang (2004) who found that sense of emotional support could be delivered implicitly through displaying sensitivity and respect. However, impersonal HCPs' attitude and relationship could hinder this chance for

emotional support which contributed to limited caregiving coping in their study.

In contrast, HCPs' dignified, and caring attitudes were reported on some occasions in this study which elicited the FCs' sense of emotional reassurance. This confirmed Gilbert et al. (2010) qualitative findings where FCs highly valued the HCPs' warm and caring attitudes that contributed to their positive cancer support experiences. Meanwhile, dealing with dignity and respect with the caring dyads could increase the sense of self-worth which contributes to the emotional security experiences of support (Funk et al., 2009, Uceda-Torres et al., 2016, Wennman et al., 2020). This sense of self-worth, appreciation and compassion appeared in this study, if HCPs equally acknowledged and responded to FCs' emotional breakdowns and showing them the commitment to their emotional well-being which also mirrors other studies (Exley and Tyrer, 2005, Funk et al., 2009, Totman et al., 2015, Lovatt et al., 2015, Spelten et al., 2019). By doing this, FCs felt able to cope with caregiving while being supported, valued and reassured through their relationship with HCPs (Funk et al., 2009, Sandgren et al., 2021, Wan et al., 2022). Thus, the present findings suggests that HCPs' skills to establish a compassionate relationships and rapport are key factors in developing the sense of reassurance and empowering FCs to manage caregiving and possible minimising their emotional distress (Sekelja et al., 2010, Oosterveld-Vlug et al., 2019).

Open clear communication and information provision formed an essential aspect of developing meaningful relationships between HCPs

and FCs. Docherty et al. (2008) qualitative systematic review found that FCs' positive interactions with HCPs was associated with the enhanced communication. This involved dedicating adequate time for listening and responding to FCs concerns and provision of honest information (Milberg et al., 2003, Barlund et al., 2021, Sandgren et al., 2021). When open communication was practiced, it contributed to an atmosphere of reassurance and emotional security (Barlund et al., 2021). This could be referred to the role of open communication in FCs' caregiving preparation and minimisation of the potential upset experienced while dealing with challenging caregiving situations (Uceda-Torres et al., 2016, Barlund et al., 2021). However, if communication was confusing and information was limited, FCs' frustration, emotional shock and caregiving chaos were heightened. This might be attributed to the problems provoked by limited or unclear communication such as difficult coping with caregiving tasks and uncertainty with HCPs' roles in the care process (Arias Rojas and García-Vivar, 2015, Barlund et al., 2021, Molassiotis and Wang, 2022).

Communication clarity regarding the PwC's diagnosis, prognosis and home support expectations at home was important for FCs in this study to develop their realistic assumptions and make decisions upon clear predictions (Gwilliam et al., 2013, Totman et al., 2015, Molassiotis and Wang, 2022). However, in several instances, HCPs' interactions with FCs increased their sense of chaos due to unclear communication which contributed to FCs' confusion and emotional distress (Totman et al., 2015, Molassiotis and Wang, 2022). This appeared in the unplanned disclosure of diagnosis, improper prognostications, and contradicting

HCPs' communication. Unclear communication about support expectations increased FCs' sense of confusion and distress which mirrors other FCs' experiences in Arber et al. (2013) study. However, the COVID pandemic uncertain context made communicating expectations about support visits more challenging. This was due to the uncertainties regarding staff availability that was impacted by their sickness and wide geographical area coverage. By contrast, when clear communication was experienced by some FCs in this study, this contributed to their sense of reassurance and emotional comfort which also illustrated by other studies (Holmberg, 2006b, Barlund et al., 2021). The authors in these studies argued that open communication with HCPs embraced a sense of relief and understanding of the prospective events. This highlights the role of clear HCPs' communication in relieving the caregiving chaos and uncertainty regarding prognosis and support expectations.

Provision of information was the second aspect of open communication that was highlighted by the present study. It would help FCs to be prepared for the caregiving process (Duggleby et al., 2017) and counteract the sense of chaos triggered by being new to caregiving responsibilities. Information provision was also important for FCs' determination of their ability to cope with caregiving demands (Bee et al., 2009, Wan et al., 2022). However, the need for information provision was declared widely by FCs in the present study which also reported elsewhere (Epiphaniou et al., 2012, Wahid et al., 2018, Bijnsdorp et al., 2022).

The information dimensions talked about in this study included disease related information, expected prognosis, practical caring tasks, and information about the support available (Harding et al., 2012, Martín et al., 2016, Barlund et al., 2021, Wang et al., 2021). This was deemed necessary for preparing FCs and building their confidence in managing the care at home (Wahid et al., 2018). Therefore, FCs felt lost, confused, and uncertain in their caregiving journey with limited provision of this information. This provoked their sense of emotional distress, lack of control, role insufficiency, and emotional insecurity (Funk et al., 2009, Bee et al., 2009, Martín et al., 2016, Barlund et al., 2021). By contrast, the findings revealed that some FCs got information only through the notion of **"Chasing and chance"**. In other words, FCs in this study chased HCPs for information, while others got information by chance through self-searching or random discussion with HCPs. Similarly, some participants in BrobÄCk and BerterÖ (2003) study reported that they only had access to information because they were proactive in information seeking process. This opportunistic information access highlights an issue of inequality; not all FCs were proactive information seekers or being able to chase busy HCPs for information so that they would not get it. Moreover, FCs are a diverse group with different neuro-abilities, literacy and language background which could be a barrier for information seeking, access and utilization (Hudson et al., 2004, Docherty et al., 2008, Adejoh et al., 2021, Barlund et al., 2021). This highlights the need for individualised approach for provision of

information that is suitable to FCs' understanding, abilities, and contexts (Doherty et al., 2016, Bee et al., 2009, Barlund et al., 2021).

Limited information provision was attributed in some instances to HCPs' reluctance to offer information that they know it would be distressing to FCs especially for prognosis related information (Johnston et al., 2012, Barlund et al., 2021). However, the majority of FCs in this study preferred being informed of the disease impact and potential deteriorations. In their qualitative study, Johnston et al. (2012) explored the patients and carers' experiences of advanced cancer at EoL and how patients' care for themselves during this period. Some FCs in their study declared that HCPs were more preservative of telling them prognostic information, since they were concerned of distressing them. However, participants in the same study reported their preference to know regardless the potential distressing impact of this information, since they perceived that lack of prognostic information was more distressing and worrying than information itself. In their critical discussion about communication and uncertainty management, Brashers (2001) argued that people differs in their responses to uncertainty according to their self-appraisal of the situation and its possible consequences. For instance, uncertainty could trigger anxiety if it hindered thoughtful decision making which triggers a sense of emotional insecurity (Brashers, 2001). However, others would view uncertain predictions as positive encounter if it sparked hope and optimism (Brashers, 2001). FCs in the present study strived for seeking prognostic information to help them for decision making and being mentally prepared. Therefore, knowing this potentially

distressing information would be beneficial for them. This might suggest that emotional distress caused by limited information and uncertainty could be greater than that resulted from disclosing emotionally sensitive information. However, HCPs should address this issue through individualistic approach; they would assess the current state of FCs' realisation of the situation and their personal preferences regarding prognostic information and the expected challenges.

Limited information could be attributed to the limited contact with HCPs. In the present study, it seemed that the COVID pandemic affected accessibility to the possible information sources such as the closure of well-being centres which was an information resource for some FCs in the study as highlighted earlier. Difficulty in getting information was also associated with the limited contact with busy HCPs in other studies (Milberg and Strang, 2004, Wang et al., 2021), which highlights the importance of considering alternative options for information provision such online and digital resources (Lavallée et al., 2019).

By contrast, some FCs in this study received valuable information through hospice drop-in sessions and HCPs' visits which contributed to their sense of reassurance that supports other studies (Mok et al., 2003, Holmberg, 2006b, Docherty et al., 2008, Barlund et al., 2021). However, information follow-up and reiteration were a concern for some FCs in the present study and deemed necessary to overcome the impact of chaotic context on information processing which supports other studies (Stajduhar et al., 2008, Caswell et al., 2015). Similarly, Bee et al. (2009) attributed this to the impact of physical fatigue as a result of caregiving

on information retention and concentration. Therefore, some FCs suggested that written resources would be beneficial as a method of information back-up (Wang et al., 2021). However, they acknowledged that this should not replace the in-person provision of information and caregiving preparation. This is in line with other studies that suggested in-person support interaction would be useful in immediate assessment and response to the FCs' information needs (Docherty et al., 2008, Stajduhar et al., 2008, Barlund et al., 2021, Wang et al., 2021).

Sharing the journey of caring was the third element of engaging in meaningful relationships with HCPs and a precursor for reassurance while facing the caregiving chaos. However, if this aspect of the relationship was diminished, it triggered FCs' sense of frustration, isolation, and exclusion. Similarly, participants argued that shared responsibility helped in developing a connection between FCs and HCPs that enhanced their relationships and embraced a sense of emotional security.

The present findings highlighted that sharing the journey of caring would be achieved through two processes that involved HCPs' regular checking and maintaining contact with FCs, and the process of involving, respecting and encouraging FCs in the caregiving journey. The present study involved some situations of checking on FCs' coping and wellbeing throughout and beyond the caregiving process and identifying their need for support which was mostly done through telephone calls in this study. The current findings also alluded that regular checking was important in HCPs' support interactions with FCs because the later tended to conceal

their suffering and needs while placing the caregiving of PwC as a priority which mirrors other studies' findings (Miranda do Vale et al., 2019, BrobÄCk and BerterÖ, 2003). In these two studies, the FCs reported that commitment to caring was more likely to distract their attention from their own selfcare and wellbeing (Miranda do Vale et al., 2019) or they found that was not acceptable to disclose their needs (BrobÄCk and BerterÖ, 2003). This highlights the significance of the notion of inclusive palliative and EoLC in which the caring dyad are the focus of support and not only PwC. In this approach, FCs are viewed as caregivers and support merit simultaneously and need checking and support (Wilkinson and Lynn, 2005, Klarare et al., 2017, Wahid et al., 2018).

The present study found that HCPs checking and follow up of FCs were mostly limited and FCs declared their intense need for checking and contact from HCPs. Limited HCPs checking on FCs' coping led to their feeling of loneliness, helplessness, and vulnerability while facing the chaotic caregiving journey. This mirrors some FCs' experiences in other studies where the lack of checking led to a sense of emotional insecurity and social isolation especially at the beginning of caregiving journey; where FCs faced the chaos of being new to caregiving role (BrobÄCk and BerterÖ, 2003, Linderholm and Friedrichsen, 2010, Ward-Griffin et al., 2012, Totman et al., 2015, Røen et al., 2018).

Lack of bereavement follow up was also noted in the present findings which supports other studies (Maddalena et al., 2010, Vierhout et al., 2019) . Maddalena et al. (2010) examined African Canadians FCs' experiences of cancer care and EoL. Participants in the study reported

lack of follow up contact especially during bereavement especially for a rural participant due to accessibility and transportation issues that hindered this to happen (Maddalena et al., 2010). Similarly, Milberg et al. (2008) using a postal questionnaire with open ended questions explored the bereavement follow up needs of family members. The authors found that half of family members reported their needs for bereavement follow up. Participants in Milberg et al. (2008) study needed this for expressing emergent emotions regarding guilt feelings of not doing enough for the care of deceased person, overcome loneliness and to be acknowledged for their contributions to care.

Bereavement follow up was reported important especially for some FCs during the COVID pandemic when informal support was limited which have increased their risk for complicated grief and emotional upset. Complicated grief is characterised by prolonged sadness and profound emotional trauma due to difficult coping with mourning situation which is more evident in the case of limited social support (Hauser and Kramer, 2004). This highlights the importance of bereavement checking for identifying any risk for complicated grief and the need for referral to appropriate support services (Hauser and Kramer, 2004, Vierhout et al., 2019).

By contrast, some of FCs in this study experienced regular HCPs' contact and checking through telephone calls and visits during the caregiving and beyond. This gave them the emotional strength to face the caregiving chaos knowing that HCPs were supporting them. This also helped in tackling ineffective coping during and beyond caregiving

journey and offering FCs the support they needed. This supports several studies that reported regular checking was an important asset in support interactions that developed the FCs' sense of emotional security and enhanced their coping and counteract their sense of loneliness during caregiving and bereavement (Wennman-Larsen and Tishelman, 2002, Exley and Tyrer, 2005, Milberg et al., 2008, Sekelja et al., 2010, Totman et al., 2015, Røen et al., 2018).

Family carers' involvement in the caregiving process and communication was the other part of sharing the caregiving journey experience. FCs' need for involvement in care communication during the professional consultations and considering their expertise in caregiving were highlighted in other studies (Harding et al., 2012, Oosterveld-Vlug et al., 2019). However, in more than one caregiving episode in this study, the lack of FCs' involvement in care communication was evident which evoked their sense of exclusion, upset and confusion. Similarly, in their qualitative investigation, Brazil et al. (2010) explored the Stress Process Model in the context of palliative cancer experience and FCs' resources for ameliorating the negative impact of caregiving. The authors of this study noted the limited FCs' involvement in treatment decisions and communication was considered among factors that increased FCs' stress. In some instances, the lack of communication involvement in this study was attributed to the living arrangement of PwC where they lived alone. In this occasion care visits and communication were mostly done regardless of the presence of FCs and without communication follow up prompt later on with them. In another instance, the hospital COVID

restrictions in medical consultations hindered involving FCs in communication where only the patient was allowed to attend, and FCs were awaiting outside. Santin et al. (2022) used an online survey with qualitative open-ended responses to explore cancer FCs' experiences and needs as a consequence of COVID pandemic. FCs in their study experienced distress due to limited communication involvement as a result of inability to attend hospital consultations with PwC during the pandemic. Limited FCs' involvement in care communication could increase their vulnerability and emotional insecurity as they lacked necessary information which would be beneficial to prepare them (Santin et al., 2022). This suggests the importance of integrating digital communication in medical consultations such as online meetings and chat software which would enable FCs in such situations to attend with PwC virtually.

The present study reported that some FCs experienced a reluctance of HCPs to accept their involvement in care during the professional visits. In other words, those HCPs imposed limits on the FCs' involvement on caregiving activities which obscured FCs' coping with caregiving. This also made them feel as an outsider, inferior, helpless, and vulnerable. However, this was not the case for FCs in other studies who were able to contribute to the care through HCPs' inclusive care attitude towards the patients and their FCs where HCPs provided care-related information, encouragement and emotional reassurance (Holmberg, 2006b, Lovatt et al., 2015, Sandgren et al., 2021). The FCs' care involvement was perceived beneficial in developing their sense of

empowerment and achievement through engaging them in care tasks (Bee et al., 2009, Holmberg, 2006b, Sandgren et al., 2021). In their systematic review Bee et al. (2009) advocated for the FCs' involvement in care tasks while being supervised by HCPs at home to help them acquire the necessary skills for caregiving. However, Levine and Zuckerman (1999) argued that family involvement in care might not be appealing for some HCPs in certain occasions where they assume that their involvement could be problematic. This could be attributed to the lack of consensus on FCs' roles in care management and the potential limits imposed on their involvement (Levine and Zuckerman, 1999). For instance, this was apparent in a caregiving situation where HCPs hindered FC's administration of injectable pain medication to her mother because this was not permitted as a FC's role. Whilst the FC perceived that she could have been authorized to perform this task, since she had accepted the caring responsibility of her mother at home, and she should be able to relief her pain. This suggests the importance of HCPs-FCs open communication about the expected roles and responsibilities and the care involvement limits. Thereby, this could minimise the potential conflicts and help FCs making informed decision about their ability to care at home.

Care involvement appeared in this study when HCPs respected FCs' views in the care process. This was facilitated through a process of roles' negotiation between FCs and HCPs and clear discussion and agreement about roles and responsibilities (Linderholm and Friedrichsen, 2010, Wennman et al., 2020, Vermorgen et al., 2021).

Consequently, this helped in support adaptation to maintain the sense of control at home and preserve some normality. Respecting the FCs as experts in care provision contributed to their sense of acknowledgement and emotional security. This could also enhance their self-efficacy, lessen their role uncertainty, and build a trustful relationship with HCPs (Funk et al., 2009, Holmberg, 2006a, Ward-Griffin et al., 2012, Tarberg et al., 2019). However, the lack of consideration of FCs' concerns was also reported in this study which mirrors other studies (Oosterveld-Vlug et al., 2019, McCaughan et al., 2019). This could led to feeling of worthlessness and insufficiency, if FCs' views and concerns were ignored, since, they considered themselves in the best position to identify and report PwC's complaints when they unable to do this (BrobÄCk and BerterÖ, 2003, Flemming et al., 2019). This feeling of insufficiency led to a potential of reluctance and hesitation in support seeking because they assumed that their concerns were usually not legitimized. This supports Richards et al. (2011) notion of **"Legitimacy of seeking help"** where some participants in their study acknowledged their hesitation and delay of calling out of hours support at the time of need because of their doubts of the legitimacy of their concerns. This recommends the importance of HCPs' giving more consideration to FCs' concerns and views regarding PwC's care.

These findings highlighted that sharing the journey of caring entailed HCPs' encouragement and positive gratitude to FCs' caregiving practice which gave them the sense of reward and reassurance. Similarly, Funk et al. (2009) noted that acknowledging FCs' efforts

enhances their self-identity which contributes to their sense of personal security. This in turn could protect against feelings of guilt and regret which might develop, if FCs felt insufficient and not doing enough regarding the care of PwC (Funk et al., 2009, Totman et al., 2015). By contrast, the lack of encouragement and appreciation of FCs' efforts would hinder developing the sense of role sufficiency, confidence and their perception of being a valuable partners in the caregiving process (Milberg and Strang, 2004, Linderholm and Friedrichsen, 2010, Totman et al., 2015, Flemming et al., 2019, Sandgren et al., 2021, Vermorgen et al., 2021).

To conclude, the current category illustrated the impact of facing the chaos of caregiving could be reduced by reliable formal support that was delivered in a timely manner and facilitated through engaging in meaningful relationships with FCs. The present theory suggested the properties of quality formal support for FCs, which was grounded in their experiences. When these properties were achieved and experienced in the formal support system, it helped FCs deal with the chaotic caregiving experience, while its absence contributed to their sense of confusion and distress. The interaction between dealing with the caregiving chaos and formal support experiences gave rise to varied emotional feelings of reward or guilt and regret. The following section discusses the third theoretical category regarding this emotional process in detail.

6.2.3. Feeling rewarded versus guilt and regret

Living in the caregiving chaos which was faced by most of FCs in this study and their formal support interactions' experiences evoked

emotional experiences of reward or guilt and regret. These feelings were experienced in different instances throughout the caregiving journey which became more evident during the bereavement. The positive and negative situations of caregiving experiences constituted two parts of the caregiving process which could happen altogether in which FCs engaged in a dual of pleasant and distressing emotions that shift and change over the time (Nijboer et al., 1998, Pope et al., 2018).

The present study found that the dominance of these emotional constructs depended on three aspects of the caregiving experience which involved the ability to manage caregiving chaos, spending quality time with PwC, and maintaining the best care and dignified death for PwC. The findings revealed that managing caregiving chaos involved significant physical and emotional work of FCs in relation to their new role of caregiving. Hence, roles' conflict was one of the significant chaos appeared in the caregiving process as highlighted in Section 6.2.1. The difficulty in balancing multiple competing roles combined with the great sense of personal commitment to caregiving provoked FCs' guilt feelings, upset and frustrations. This was clearly evident, if role insufficiency was perceived for any responsibility FCs had. Similarly, Martz and Morse (2017) echoed this in their theoretical model associated with feelings of guilt in the process of EoL transition where role conflict was a triggering factor for these guilt feelings. This illustrated that importance of FCs' encouragement in their caregiving journey and the role of informal family network and HCPs in resolving the dilemma of roles' conflict through direct support with competing roles.

Similarly, the current study found that these feelings of guilt were exaggerated when FCs realised their physically insufficiency to provide the level of care they wished and their inability to meet the support needs of PwC. In some instances, this resulted in FCs' ignoring their health complaints to attend to their duty of care with the uncertain rapid prognosis of PwC being in their mind. This was rationalized by FCs' endeavours to avoid feeling guilty, if they realised that they did the best they could in their caregiving commitment towards PwC. However, other FCs were not able to conceal their suffering so that feelings of guilt were developed, this appeared in a caregiving situation where FC was suffering and crying from physical complaints attributed to caregiving of her mother. However, she felt guilty of display suffering and distress while caring for her mother during EoL. This could indicate a development of an emotional conflict and dilemma that FCs might experience in which emergent roles and priorities, FCs' abilities, and PwC's rapid prognosis contradicted. This would increase FCs' distress and emotional upset.

In their sociological study about the variations in the emotional experiences of cancer FCs, Olson and Connor (2015) argued that when FCs cared for a dying person their roles and priorities were clear. Hence, FCs realised the primacy of PwC's care and engaged in an emotional labour of setting their negative feelings aside to appear strong to PwC and fulfil their expectations as a supportive FC (Olson and Connor, 2015). This could explain the reasons of emergence of guilt feelings

when FCs were unable to hide their suffering and felt insufficient and beyond the expectations of a supportive FC.

A latent sense of regret for losing support opportunities was another emotional construct experienced by some FCs in this study. Those FCs assumed that they could have accessed more support, if they were proactive in support seeking which could have helped them to cope more effectively. They attributed this to the chaotic caregiving context that clouded their mind and affected their support seeking behaviours. However, ignoring own needs was the FCs' response which echoes Olson and Connor (2015) argument highlighted before about prioritising PwC's needs. Some FCs in Olson and Connor (2015) study reported potential guilt feelings could emerge if they considered their own support needs. This indicated the importance of HCPs' checking and signposting FCs to support services as necessary.

The present findings illustrated that the ultimate aim of providing EoLC at home for many FCs was to maintain the sense of normality and having quality time with PwC. Therefore, FCs developed a rewarding experience and a sense of achievement if they were able to achieve this aim; knowing the time restrictions imposed by the prognosis which mirrors other several studies (Hauser and Kramer, 2004, Li and Loke, 2013, Olson and Connor, 2015, Totman et al., 2015, Leow and Chan, 2017, Pope et al., 2018, Spelten et al., 2019). This might be attributed to the idea that home environment could embrace a sense of familiarity, safety, and security (MacArtney et al., 2016, Barlund et al., 2021), which would facilitate spending quality time. This was achieved through

practising social activities and routines that FCs and PwC used to do prior illness without being affected by medical environment context. The safe and flexible environmental characteristics of home setting were clearly evident in the caregiving episodes during the COVID pandemic; quality time was spent away from visiting restrictions at the hospice or the hospital which also supports other FCs' experiences prior the pandemic (Spelten et al., 2019). This was also confirmed by another COVID study that compared EoLC experience of bereaved relatives in different settings that included home, hospital, nursing home, and hospice during the pandemic (Yildiz et al., 2022). Majority of participants considered home death as appropriate and the authors of this study attributed this to the limited visiting restrictions at home as one of the reasons for this preference (Yildiz et al., 2022).

By contrast, expressions of regret were reported in the present study when FCs were unable to spend quality time as they wished. Leow and Chan (2017) mentioned that participants in their study were frustrated and felt guilty due to inability to spend enough quality time with PwC. The present findings found that the overwhelming caregiving tasks had an impact on limiting the time spent with PwC. However, for some FCs quality time experience was affected by the notion of identity conflict and role ambiguity that some FCs experienced. This role ambiguity would make FCs to focus on caregiving while ignoring other important experiential aspects such as, making memories or spending more quality time, sharing emotions and conversating with PwC which contributed to the regret feelings afterwards. This could be attributed to the shared

relational similarities that exist between caring, familial and friendship ties where clear boundaries would be vague. Similarly, Olson and Connor (2015) reported a significant emotional challenge associated with being a carer and spouse where the distinct features and boundaries of both roles were confusing to spousal FCs. Meanwhile, FCs in the present study perceived that if more support at home was granted, caregiving chaos and role identity conflict would be lessened, and they could have enjoyed quality time with PwC. This supports other FCs' perspectives in Exley and Tyrer (2005) study, who were frustrated about the delay in organizing support at home and delayed discharge that led to losing quality time could have been spent at home.

Family carers' ability to provide quality care and support to PwC and achieve dignified dying formed the third part of their experience of reward or guilt and regret. The present findings noted that a sense of achievement and reward was experienced when FCs realised their success in providing quality care at home for PwC which had a positive repercussion in their coping with grief (Spelten et al., 2019).This supports other research that indicated FCs became proud of their achievement in caregiving process which enhances their self-efficacy (Hauser and Kramer, 2004, Linderholm and Friedrichsen, 2010, Anderson and White, 2017). In the current study, the feeling of pride and reward resulted through identification of other gains in the caregiving process such as satisfactory relationships with PwC, the ability to show them love and commitment through caring, and enhanced sense of self-identity through the notion of helping the others and contributing to their care (Nijboer et

al., 1998, Li and Loke, 2013, Brown and Brown, 2014, Leow and Chan, 2017). Li and Loke (2013) in their critical review about positive aspects of caregiving for cancer patients mentioned that the sense of self-efficacy is a pre-requisite for identifying positive experiences and rewards of the caregiving process. However, this study added that FCs' self-confidence and efficacy would have a mutual relationship with successful caregiving journey. In other words, it could act as a facilitator for coping with caregiving chaos. Besides, it would be an emotional outcome of successful and rewarding caregiving process. These findings revealed that the sense of accomplishment and reward, which was gained through the success in caregiving journey was fostered through HCPs' acknowledgement of FCs' efforts. This highlights the importance of HCPs' encouragement for developing this positive emotional experience of reward (Dumont et al., 2008, Martín et al., 2016).

Dignified death at home was another rewarding experience for FCs who were able to facilitate for PwC by helping them to stay at home. Dignified death was fostered through the distinct properties of home settings such as familiarity, emotional comfort, privacy, and being surrounded by the family members and friends (Topf et al., 2013). This study suggested that professional support at home was a facilitator for this positive experience to occur through the provision of the context of emotional reassurance and opportunity to stay at home until death. When this occurred, it provided FCs with an appropriate closure for the caregiving journey while being able to say goodbye to PwC; this provided them with a rewarding spiritual experience (Li and Loke, 2013).

Whilst feeling guilty, self-blame and regret would be prominent if wishes for dignified death at home were threatened due to PwC's suffering and the challenging complex care management at home. This meant that the existing place of care and death decisions would change by PwC's possible admission. This was perceived by some FCs in this study as a failure that triggered their guilt feelings which mirrors experiences of FCs in Topf et al. (2013) study who explored FCs experiences when desired home death for PwC was not achieved. Meanwhile, these feelings of guilt due to admission would increase if this was not the preferred option for place of care and dying as well as it was perceived as breaking the promise to support PwC at home until the end (Martz and Morse, 2017, Topf et al., 2013). The present findings alluded that these feelings were also heightened if care transition was perceived as an inappropriate decision that contributed to a non-dignified death experience for PwC (Martz and Morse, 2017).

This was more evident in some FCs situations during the COVID pandemic when the care transition was perceived as a distressing experience that did not allow for a dignified death to take place. In such situation, a FC was deprived from accompanying her husband everyday as she assumed due to COVID visiting restrictions at the hospice. This was compounded by her husband's COVID infection and isolation which was opposite the notion of a dignified death; being surrounded by the family while dying as evident in other FCs situations as discussed earlier. These guilt feelings could continue into bereavement and might trigger

complicated grief due to inability to achieve the dignified death as promised (Topf et al., 2013).

However, if care transition decisions were perceived in PwC's best interest, these guilt feelings were lessened which mirrors other studies findings (Martz and Morse, 2017, McCaughan et al., 2019). In some instances, these negative feelings could not be easily overcome due to perception of broken promises of facilitating dying at home (McCaughan et al., 2019, Topf et al., 2013). This highlights the importance of bereavement follow up for identifying these emotional concerns and difficulties (Topf et al., 2013, Vierhout et al., 2019).

Some FCs in this study assumed that if adequate support was provided at home, dignified home death could be achieved, and a rewarding experience could be attained rather than feelings of guilt which supports several authors claims (Sekelja et al., 2010, Chapple et al., 2011, Li and Loke, 2013, Topf et al., 2013, MacArtney et al., 2016, McCaughan et al., 2019). However, this should be interpreted with caution, since FCs' support expectations would greatly differ from what would possibly be provided at home setting (Topf et al., 2013). In other words, community palliative care support at home would not be a guarantee for home death, since the access to institutional care with specialized resources might be needed to meet the changing caring needs of PwC and achieve the notion of dignified death (MacArtney et al., 2016, Martz and Morse, 2017). Therefore, the place of care preferences could change if PwC's suffering increased and FCs felt vulnerable to provide care at home which was evident in the present

study (Lysaght Hurley et al., 2014). This highlights the importance of raising the awareness of FCs about the possible change of the place of care in response to potentially challenging caring needs therefore, guilt feelings associated with care transitions could be minimised.

This study supports the theoretical interpretation of experiences of reward and guilt in the caregiving process which was explored in other studies (Carbonneau et al., 2010, Li and Loke, 2013, Martz and Morse, 2017). However, it provided further explanation of the dynamics of these positive and negative emotional experiences while facing the caregiving chaos and highlighting the crucial role of the formal support in this process. Interpreting these emotional experiences of reward or guilt and regret would enhance the theoretical explanation of the predictors and determinants of these emotions in the caregiving process (Nijboer et al., 1998, Li and Loke, 2013). This could help to define support strategies and interventions to promote the positive emotional experiences and lessen the impact of the negative encounters (Nijboer et al., 1998, Li and Loke, 2013).

6.3. Chapter summary

This chapter discussed the proposed theory of **“Facing the caregiving chaos in the light of formal support”**. This theory highlighted the different properties of chaotic caregiving experiences and identified FCs’ coping ways with caregiving chaos. It also revealed the role of formal support in this process and illustrated how formal support experiences mediated the effect of the caregiving chaos. Lastly, the present theory highlighted the essence of sequential emotional experience of reward or guilt and regret, which resulted from the interaction between living and coping with the caregiving chaos and interacting with formal support experiences.

CHAPTER SEVEN: CONCLUSION

7.1 Chapter introduction

This chapter discusses how the study aim and objectives were achieved in relation to the study findings. It highlights the contribution of this study to the body of knowledge and its implications for policy, practice, education, and research. A critical appraisal of the present study will be discussed, and the chapter will conclude with a summary statement of the main highlights of this PhD study.

7.2. Achieving study aim and objectives

The overall aim of the study was to explore the FCs' experiences and perceptions of using formal support services received while caring for PwC at EoL. This was addressed in the study overall findings and the developed theoretical interpretation. Overall, the study specific objectives were accomplished and represented through the developed qualitative categories. The first category addressed the caregiving chaotic context and identified various situations that FCs would need more support which met the second objective of the study regarding exploring situations where FCs needed more or less formal support. Meanwhile, the third category regarding reward or guilt and regret experiences also illustrated the different situations where formal support would contribute to each emotional construct of this experience.

The second category addressed the experience of formal support interactions which highlighted FCs' views about formal support which was the first objective. This category also identified factors that would either facilitate or constrain the process of formal support which

addressed the third objective of the study about these factors. The second category also described situations where FCs' expectations about individualised support were not met which addressed the fourth objective about FCs' perceptions on the extent to which formal support matched their expectations. The three theoretical categories suggested improvement points by highlighting the positive and negative encounters with formal support. This met the fifth objective of the study about development of recommendations for service improvement.

7.3. What this study adds?

The present study contributes new knowledge to the cancer caregiving at EoL literature. It facilitated the in-depth exploration of the caregiving and formal support processes through the grounded theory approach. This study added to the existing caregiving knowledge by providing a theoretical explanation of the link between caregiving chaotic experience, formal support interaction and the overall emotional experience of caregiving journey that encompasses reward or guilt and regret feelings.

The proposed theory also added to our understanding of the psychodynamics of positive and negative aspects of caregiving process and its relationship to formal support and the contextual factors that influenced this process. This contributed to the research gaps identified by Li and Loke (2013) in their critical review of positive aspects of caregiving that found uncertain arguments regarding the contextual factors which would foster the development of positive caregiving experiences. This was achieved in this study by explaining the processes

underpinning the sense of reward or guilt and regret such as, managing caregiving chaos and spending quality time. Similarly, this study signposted the contextual background to this emotional experience of reward or guilt and regret such as, the presence supportive formal support interaction and FCs' ability to cope with caregiving chaos which favoured certain emotional construct over another.

The present study added further credibility to some aspects of Martz and Morse (2017) theoretical model **"The changing nature of guilt in family caregiving"** that described the FCs experiences of guilt throughout care transition when a dying parent couldn't stay at home until EoL. The present theoretical categories identified some guilt incidence conditions such as, roles insufficiency and conflict mentioned in Section 5.7.1 and the sense of failure when admission occurred as highlighted in Section 5.7.3. This addressed Martz and Morse (2017) recommendations for further exploration of the guilt construct and its resolution in FCs.

Generally, this study bridged the knowledge gaps identified in the narrative review and responded to the research implications suggested in Section 3.5.3. For instance, this study explored the support construct through wide range of services and exploration of contextual factors that shaped the support experiences as highlighted in the second theoretical construct Section 5.6. This was achieved through identifying positive and negative situations of formal support interactions and illustrating their properties and conditions that contributed to either satisfactory or negative FCs' experiences. This study added to the small number of

studies that explored FCs' experiences in multiple caregiving stages. This was achieved through including FCs who were current or former FCs as well as those in the post bereavement period which facilitated exploration variety of FCs' support experiences in different situations and caregiving stages.

Although this study was planned prior the COVID pandemic, data collection was conducted throughout the pandemic which helped in exploration of FCs' support experiences during the international crisis. Hence, this theory was uniquely developed through a lens of a worldwide crisis of COVID pandemic which impacted the majority of FCs' episodes. This added further contribution to the knowledge regarding EoLC during human crises which would guide developing strategies for proper support practices during these kinds of disasters whenever happened in the future.

7.4. Study implications

The present findings suggest several implications that would inform policy, practice, education, and research. In the next sections these implications will be explored in detail.

7.4.1. Policy implications

A plethora of UK social policies, regulations and action plans were developed for FCs' support over the recent years. These policies provided directions for developing strategies to support FCs such as the Care Act 2014 (UK Government, 2016) and the Carer action plan 2018-2020 (Department of Health&Social care, 2018). Although, these policies provided general framework for FCs' support which would be applied to

all conditions, considerations for FCs' support during EoL period were still limited (Payne and Hudson, 2008).

7.4.1.a. EoL specific policies

The UK EoLC strategy (Department of Health, 2008) highlighted the importance of FCs' support during this period; however, unmet support needs are still evident. This study revealed the special nature of EoL stage which would differ in their experiences depending on the disease trajectory as highlighted earlier in Chapter two. Therefore, FCs' support policies should consider and endorse the urgency and specific nature of EoL stage. As indicated in this study, those group of FCs faced a great disruption in their life due to the terminal diagnosis and the associated caregiving tasks besides their other commitments. They also experience difficulty in self-navigation of various support, chasing and long waiting for support related arrangements which did not conform with the limited time available at EoL. Therefore, EoLC specific legislations are needed to facilitate the access to FCs' support services in a short time. Although the EoLC fast-track approach is present in the UK practice (Department of Health&social care, 2022), prognostic uncertainty, services' pressures and resources limitation should be acknowledged which might impact the urgency of meeting support needs (Moback et al., 2011). A focus on FCs' support needs assessment would need to be emphasized in this fast-track approach. Thereby, performance of FCs' needs assessment at EoL should be stated in a specific timeline qualifier that congruent with the time range of 48hrs of fast-track strategy. In doing so rapid assessment and support access could be facilitated for both; PwC and FCs equally,

since support timing is a detrimental factor for its satisfaction and acceptability (Nolan, 2003).

7.4.1.b. Work support

It was evident that work responsibilities were integrated with caregiving tasks in the most of adult family caregiving situations. This resulted in significant physical and emotional burden and roles conflict that contributed to the sense of chaos. The existing work policies either give FCs the choice of flexible working or a limited short period of unpaid emergency leave (Payne and Hudson, 2008). By looking at the UK FCs' work policies, it seemed to provide limited choices for FCs which lead them to continue work and depend on informal network for caregiving which is not feasible in most cases. Whilst others would take a leave of absence, if this is the only appropriate choice. However, the context of EoL caregiving and the prognostic uncertainty make it difficult to anticipate the time of intense need for this work leave, similarly, it is unpaid leave that threatens the level of family income (Bijnsdorp et al., 2022). Thus, this study recommends a review of work policies for FCs who support people with terminal diagnosis and offer them a paid caregiving leave for a considerable period of time. If this is achieved, they could dedicate most of their time for caregiving without concerning about their income level.

For instance, in Canada, the FCs providing care for a dying relative in the last six months of life are entitled for six weeks paid **"Compassionate leave"**; however, it provides up to fifty-five percent of their income (Williams et al., 2006). In another context, the Swedish model contends

a work leave for up to one hundred days with eighty percent of work income for FCs of people with terminal diagnosis supported with a medical certificate (Colombo et al., 2011). This approach provides increased level of income for extended period than the Canadian model. However, both approaches are restricted by the notion of terminal state that undermines the challenges of precise prognostication of terminal diagnosis (Williams et al., 2006). In Norway, paid leave is specified for employed FCs without a restrictive criteria of terminal prognosis which provides a flexible approach for this support; however, it is provided only for a limited period of twenty days of full work income than other models (Payne and Hudson, 2008). These models of work-leave policies could provide a valuable guidance for developing similar ones that could be piloted in the UK context. However, the issue of prognostic uncertainty should be addressed with reasonable flexible period of leaves that could be distributed over the whole period of caring with sufficient income reimbursement.

Although flexible working conditions exist in FCs' policies, which mostly refers to part-time working, its implementation would be affected by the employer's consideration of the FCs' employee situation (Colombo et al., 2011), and the awareness of employees about their work support rights which was evident in this study. For instance, in the UK, FCs would be entitled to flexible working arrangements for indefinite duration; however, they must be a first degree relative for the person requiring support. Whilst, in other countries such as Netherlands, provision of such support is subject to an agreement with the employer, which would limit

access to this type of support (Colombo et al., 2011). The present findings illustrated varied flexible working conditions that were enforced widely in the COVID pandemic, such as remote working and furlough scheme which had a positive impact on the FCs' coping with caregiving responsibilities. Thereby, similar policies would be in place to support FCs who are caring for people with terminal illness. However, caring status should be acknowledged without being restricted to certain degree of kinship (e.g., first degree relative) and disseminated across all sectors to offer FCs this kind of support. This requires a system of communication between healthcare system, social care, and the employers to ensure sharing of caring information and the delivery of support needed (Bijnsdorp et al., 2022). Other FCs who work in essential services, such as NHS and Police, flexible working might not be feasible; a short-term redeployment for administrative or other related work would be suitable for remote working could be a solution for this dilemma. However, challenges such as staff shortage in these sectors should be acknowledged that would hinder the application of this recommendation.

7.4.1.c. Support allocation

It was apparent that social care support through homecare visits is determined based on the needs assessment of PwC and family context. Although, it was provided free of charge for FCs in this study, it was for a maximum of four visits per day considering that PwC would receive support from the informal network. However, the present findings suggest that aspect of support care regulations needs review where the number of support visits could be increased especially for people with

complex needs and limited informal support network. This problem of inadequacy of support visits was most apparent in the COVID pandemic when some FCs lacked support from their extended family due to the lock down. However, the increase in service capacity would be challenged by the limited funding available for such services. An enhanced collaboration between formal services and voluntary sector such as charity-based hospices and support centres would help in bridging this gap through the work of volunteers (Colombo et al., 2011). However, the challenges of clinical supervision and training for community care volunteers should be acknowledged which would involve HCPs and formal support indirect costs (Morris et al., 2017). This would suggest the need for flexible approach of support visits rather than providing a set number of visits and hours which could be either in excess or less than required as evident in this study. This flexible approach would consider the changing nature of caring needs and FCs' contextual factors such as their ability to provide care and availability of informal support. Hence, the number of support visits would be changed flexibly based on the support needs that is regularly assessed.

Another critical point for the support visits allocation was the need for PwC's approval for supportive care which placed some FCs in a dilemma if they need support in practical tasks, but it was refused by PwC. This could lead to FCs' psychological distress and upset and would impact FCs' ability to continue caregiving at home. This suggests the need for open discussion with PwC and FCs about the support needs and possible impact on FCs coping and overall care continuation at home, if

formal support was refused. Further strategies could be in place such as help with outdoor caregiving activities (e.g., medication collection, and care coordination) and support with household tasks (e.g., shopping, and cleaning) for vulnerable FCs who would need care support in the presence of PwC's refusal.

7.4.2. Practice and education implications

Various practice guidelines and strategies were developed to guide the process of supporting the person with terminal illness such as cancer and their FCs at EoL such as EoLC strategy (Department of Health, 2008) and the Care of dying adults in the last days of life guidance (NICE, 2015a). However, the wider application of these guidance and strategies seemed to be limited in some respects such as the feasibility of care transition, out of hours support and provision of person-centred care which will be highlighted in the following sections.

7.4.2.a. Care transition and coordination

Although a wealth of healthcare recommendations and strategies aim to facilitate care transitions between settings through care coordination and HCPs' collaboration (NICE, 2015b), this process still faces difficulties as illustrated in some study situations. Transition pathways from secondary and tertiary care to community care (i.e., home setting) need to be addressed with definite timelines and follow up determined in the discharge plan of care. Therefore, home care package should be promptly arranged prior discharge to ensure safe and comfortable stay of PwC. Although a practice policy for fast-track continuing healthcare at home exists that provided a framework to ensure access to care within 48 hrs (Department of Health&social care, 2022), the present study

highlighted variations in the application of this policy. This appeared in some caregiving situation where care packages were delayed, and FCs experienced significant distress.

A Marie Curie report (2017) explored the fast-track application in England through a freedom of information request to NHS trust and Clinical commissioning Groups (CCGs). They found time variations of care package arrangement within 48 hrs with about two thirds of people waiting for more than one a week for care package (Marie Curie, 2017). This was attributed in some instance to Monday-Friday working time of processing the application for fast track services and limited services capacity that cause a delay in care package arrangement (Marie Curie, 2017). However, on a wider scale, some barriers are existed regarding the improvement of fast-track framework that involved challenges of data reporting of good practice of implementation, service audit and staff training inconsistences (Marie Curie, 2017). This study supports the recommendations of further staff training regarding the fast-track framework and facilitate information sharing of best practice implementation to be used by other healthcare organisations (Marie Curie, 2017). This study also encourages regular local and national auditing of this service to highlight concerns and suggest proper solutions (Marie Curie, 2017).

The care transition from community to secondary and tertiary care for a palliative care individual should consider the promptness and urgency of referral if the person developed complex and uncontrolled symptoms. However, a delayed transition process due to rigid local healthcare

transition regulations such as, the need for referral by a hospice during regular working hours made some FCs in this study feel desperate and insecure while providing caregiving at home. These regulations need reviewing to enable feasible access to acute care in a prompt time so that FCs would feel reassured about support access as highlighted in findings Section 5.6.1.b.

Lack of coordination of support and difficult navigation are recurring themes in healthcare services' studies (Oosterveld-Vlug et al., 2019, McCaughan et al., 2019). The present findings highlighted the need for developing systems and strategies to ensure robust channel of communication between different levels of support; primary, secondary, and tertiary care to facilitate easy allocation of support services without chasing from FCs. This could be achieved through the implementation of support coordinators that would help FCs in support navigation (Adejoh et al., 2021). Similarly, this study suggests the expanded implementation of volunteer support and coaching provided by former FCs who would act as a buddy/tutor for other FCs guiding them in support navigation and the practice of their new roles at EoL. **"Death doula"** is a model for supporting dying individuals and their families which is already implemented in the UK to provide emotional, spiritual, decisional, and practical support (Newland, 2021). This service is personally funded; however people would apply for free of charge service if they couldn't afford it (Newland, 2021). This study suggests raising the awareness of the palliative care stakeholders (e.g., patients, FCs, HCPs) about the benefits of this service in supporting palliative care individuals and FCs

and relieving the potential FCs' role strain through provision of practical support and respite (Krawczyk and Rush, 2020).

7.4.2.b. Out of hours and support response

Out of hours support is an important aspect of palliative and EoLC at home (Richards et al., 2011). However, this study indicated that the process of access of out of hours support needs improvement. For instance, there is a need for the specific allocation of the same group of HCPs responding to a defined group of PwC to ensure the feasibility of support access and ensure the continuity of care. Furthermore, out-of-hours pain management at home was experienced as a significant problem regarding the timely availability and administration of opioid medications for pain control. Although current guidelines advised about prompt opioids provision and administration for pain control during the palliative phase (NICE, 2012), limitations were still experienced especially during the out of hours as evident in some FCs situations in this study. Limited out of hours community pharmacy services which would provide pain medication was one of the issues highlighted by this study. Meanwhile, the wide expansion of out of hours community pharmacy services' coverage is recommended, this would be challenged by incurable costs regarding direct fundings and staff availability. Therefore, this study proposed a health services commissioners' agreement between community and secondary care organizations (e.g., hospitals) would exist for medication provision in areas where out of hours community pharmacy services are limited.

Practice restrictions regarding FCs' administration of injectable opioid medications was another issue mentioned by some FCs in this study. Even if medication was available at home, FCs experienced long waits for HCPs as they were not allowed to administer these medications. Risk assessment and training of FCs' ability to engage with this medical task could reduce the caring dyad's suffering due to delayed access to pain medication. However, this requires strict coordination, coaching and follow up from an expert HCPs which would contribute to increased HCPs' time cost.

7.4.2.c. Provision of family/person-centred care

The findings highlighted the importance of family-centred care. This would be achieved through HCPs-FC's care conference that involves the discussion of the care package and its adaptation to caring dyad's preferences and needs. The theoretical interpretations suggested by this study could be used in HCPs' meetings with FCs to explore the issues contributing to their experience of caregiving chaos (e.g., competing responsibilities). This would help identifying their support needs and offer them an individualised support matched to their circumstances.

The study indicated that the process of FCs' preparation is crucial for their involvement in the caregiving process upon roles and responsibilities negotiation with HCPs. Thus, a planned FCs' preparation through information provision and practical skills tutorials based on informative needs assessment is recommended to develop their sense of sufficiency. Continuous follow up for information should be done

regularly considering the impact of chaos imposed by caregiving process on their attention, understanding and retention of information.

People with cancer's response to illness and caring dyad's relationship was evident in influencing FCs' caregiving experience. Therefore, FCs' education about PwC's reactions towards terminal illness and how to deal with negative responses would be important. Similarly, raising caring dyad's awareness about the positive aspects and contributions of informal caregiving would help in realising the caregiving process rewards and minimise the incidence of the strained relationships. However, HCPs should pay attention to the existence of strained relationships through their discussion with the caring dyads and offer counselling opportunities whenever needed and accepted (Stajduhar et al., 2008). Family-centred approach for support could be achieved through HCPs' regular checking and contact with FCs to provide encouragement and emotional support and highlight their achievements in the process. This would also identify FCs' negative emotions and potential psychological distress and refer them for appropriate support needed.

This study recommends that individual differences in the support needs should be considered to achieve person centred care ethos as one size of care does not fit all. For instance, some PwC had complex needs which required several daily support visits during which sometimes would place distress on FCs with limited informal network. The flexible approach to support allocation highlighted in Section 7.4.1.c would be an option for addressing this issue. Furthermore, the use of

digital technology and telehealth as mentioned in Section 6.2.2. would be a practical option for complementing in-person support visits. However, the idealistic instance for this problem is expanding the working hours of services and facilitating the wider application of live-in care for PwC who have complex needs to secure around the clock support. However, this would be restricted by healthcare funding limits and staff shortage (Wahid et al., 2018). Therefore, investment in trained volunteer support could bridge this gap as discussed in Section 7.4.2.a. Meanwhile, allocating more financial resources to healthcare system to facilitate support equality is still a desirable ambition.

7.4.2.d. Disaster action plan

Accessibility and availability of support services could be affected by national disasters and crises such as the global COVID pandemic which was the case in this study. Therefore, regular assessment of health services resources is essential to ensure stability and running of the services during any potential crises. A regularly reviewed mitigating disaster plans should be in place and all HCPs should be aware and trained on them; especially for disasters that exerts impacts on healthcare services and resources such as pandemics. The learned lessons from the pandemic formal support experiences noted the importance of extended use of digital technology in provision of support. This would be achieved through investing in virtual support visits and consultations to reduce travel time and offer emotional support for FCs whenever needed; however, it should not completely replace the regular in-person interactions. Furthermore, FCs' support groups and wellbeing

meetings could be arranged on hybrid mode; even in non-disaster related context; where it would suite FCs in different circumstances and enable them to attend either in person or virtually.

7.4.2.e. HCPs' education and public awareness

Healthcare professionals' education and training is an essential aspect of quality palliative and EoLC (Hansford and Meehan, 2007). This study suggests that basic palliative care knowledge and skills should be incorporated in medical curriculums. This would facilitate that all HCPs have the basic knowledge of palliative care issues necessary for provision of palliative support in all levels of care. The present study revealed that communication skills training deemed necessary for developing skills to engage in quality relationships with caring dyad which was second dimension of support interaction experience that was revealed by the present findings (Marco et al., 2022). Furthermore, HCPs could be trained on how to support FCs particularly during the last year of life of person with terminal illness while integrating the disease trajectory. This would enable them to promptly identify FCs' support needs and signpost them to proper resources reflecting their caregiving trajectory and rapid uncertain prognosis of some people with terminal illnesses.

The present findings identified dimensions of rewarding experiences and drivers of potential guilt and regret feelings. This suggests the importance of HCPs' awareness of the psychodynamics of caregiving process during EoL caregiving experiences and beyond for dealing with FCs' collective experiences and issues. Thereby, the present model

would be useful in HCPs' training to discuss FCs' support needs for developing favourable rewarding experience throughout caregiving and beyond and minimise the emergence of guilt and regret emotions.

Likewise, HCPs' education, this study recommends the need for raising public awareness about the importance and potential perceived benefits of family caregiving. For instance, this would involve the potential emotional wellbeing of the caring dyad; if they developed positive caregiving relationships as illustrated by Li and Loke (2013) critical review about positive aspects of caregiving. Public should also be aware of their potential positive societal economic contribution through healthcare expenditure saving when care is provided at home whenever possible (Hauser and Kramer, 2004). Building FCs' friendly communities would be a proposed initiative to disseminate the caregiving culture and support throughout the society. This could be achieved through educational campaigns for different community sectors about caregiving. This could encourage community members in considering the toll of caregiving and offer help to FCs in the local communities. Furthermore, the present findings suggest raising the awareness about the concept of family shared contribution for care among families; caregiving being shared evenly among family members; this could minimise the burden felt by an individual FC.

7.4.3. Research implications

Family carers' research is increasing to explain the different aspects of caregiving practice and provide recommendations for FCs support strategies development. This study identified a theory that explained the

experience of a group of FCs of PwC at EoL. However, further research is needed to test the relationships between various components of the proposed theory and explore the emotional transitions between the sense of chaos and reassurance feelings and their relationship to reward or guilt and regret. Future studies would explore the role of formal support interactions in maximising positive emotional rewarding experience and minimising the negative ones. Further studies could explore the identified mutual relationship between self-efficacy and the self-actualisation through reward feelings in caregiving process. Although this theoretical interpretation was developed for cancer related experience, other studies would explore these theoretical interpretations with other terminal conditions and/or people with multiple comorbid conditions.

The study highlighted that COVID pandemic had both positive and negative impact on caregiving process. Further research is needed to investigate the long-term pandemic impact on FCs' palliative home care experiences. Studies would investigate how FCs and HCPs dealt with these COVID impacts and spotlight the good practice. Other studies are needed to explore the efficiency of digital technology interventions in FCs emotional support. This study identified various ways that informal support network operated within the family; however, studies would investigate the family shared contribution for care approach which was described in Section 7.4.2.e and the associated family dynamics.

Future studies are recommended to explore the palliative care support experiences using larger samples of FCs while focusing more on those who are currently caring and those in resources poor settings.

Comparative studies for exploring FCs' support needs while caring for individuals with various types of cancer in various trajectories would add more understanding to the support needs differences between FCs. However, studies would focus more on the specific types of FCs e.g., young, old, working, ethnic minorities FCs to develop contextual specific support strategies.

Meanwhile, studies involving other key individuals in the caregiving process; HCPs and people with terminal illnesses are needed to explore their perceptions of FCs' support at EoL. All these approaches would help the development of innovative FCs supportive interventions which could be tested using feasibility studies and Randomised Controlled Trials (RCTs) adopting ethical standards to guide FCs' support practice. Lastly, there is increased need for the provision of more fund and grants for FCs' research projects; that specifically evaluate the current FCs' social policies, provide precise evidence regarding its usefulness, and suggest recommendations and amendments based on the changing societal needs.

7.5. Study critical appraisal

Several evaluation tools exist to critically appraise qualitative research, in this study **"The framework for assessing qualitative evaluation tool"** (Spencer et al., 2004) was used. This tool was preferred due to its comprehensive approach and availability of guiding questions to facilitate the evaluation process. The full assessment report is provided in (Appendix 8.). Critically appraisal of this study helped in

figuring out the strengths and limitations that would be useful signposting the merit of the study and guiding the development of future studies.

7.5.1. Strengths

This study explored FCs' experiences in different stages of caregiving journey (i.e., current, former and bereaved FCs' experiences), which allowed identifying their perspectives over a wide scale of support services. It also facilitated exploring the principal ethos of support experiences which could be applied for any kind of support as highlighted in Section 5.6.

Considering the contextual nature of qualitative research, doing this kind of research by a non-native researcher added further validity to other studies in the field depending on an outsider view. Furthermore, the study reported on FCs experiences with the majority of caregiving situations occurred within the COVID pandemic with some pre-COVID caregiving experiences. This combination of experiences facilitated identifying the response of the services during this unprecedented time that would help informing strategies to overcome the future challenges. The rigorous study inclusion criteria helped to focus the study orientation to the support provided in the last year of life which was limited in other studies as highlighted in Section 3.5.3. of the narrative review. This study included FCs in different caregiving stages with different caring relationships who cared for PwC of any cancer diagnosis. This provided varieties in data sources and maximised the utility of these findings to a wide array of FCs' population.

Formal support experiences have been mostly explored in the previous studies using general descriptive approach. Adopting an interpretative analytical approach; CGT allowed for deeper analysis of caregiving and support experiences and develop the present theoretical model. Whilst the use of constructivist approach allowed for flexible and iterative nature of data collection (i.e., qualitative interviews) and focusing on the issues that were important to the participants while conforming to study aim and objectives. The present study combined various recruitment strategies such as, standard recruitment through formal gatekeeping, social media and internet recruitment. This increased the recruitment coverage and allowed for sample variability and exploration of formal support experiences across various localities. The PPI component in this study allowed for appropriate ethical planning for the study and interview questions that would be meaningful to FCs and make new contribution to the knowledge.

7.5.2. Limitations

The primary FCs were the focus of the study; however, in minor occasions it was difficult to establish this fact since it was based on FCs' self-assessment of their status as primary FCs. Furthermore, the notion of caregiving teamwork appeared in this study made it difficult to specify one FC as a primary in some instances. Although, this would be seen as a limitation, it shed the light on the caregiving teamwork approach in some families. Future studies would benefit from defining FCs in relation to their regular contributions to care of PwC. The study cross-sectional approach involved a single interview could be a limitation. In other words,

this would have minimised the opportunity to examine the experiences over the time; the use of multiple interviews with the same participant would have helped in achieving further clarity of their views and allowed for member checks. However, the study design decisions were considered in the light of the sensitive nature of the interview and the possible distress would be elicited if longitudinal interviews were planned. Moreover, the prognostic uncertainty of terminal illness would hinder the possibility of subsequent interviews for current FCs. The use of constructivist approach enabled adapting and focusing interview questions for subsequent interviews without the need for a follow up interview with the same participant.

The ultimate use of remote rather than in-person interview would have been a limitation that negatively impacted the rapport building and capturing the nonverbal communication. However, as highlighted in Section 4.5.5.b, the introductory messages and calls facilitated rapport building and discussing FCs' experiences in depth as intended. The use of video calls and considering the tone of voice also helped to capture nonverbal communication cues.

However, some problems were experienced with the consenting procedures due to the remote nature of research interview. In some instances, unfulfilled promise to receive the written consent following the interview led to excluding one interview prior transcription and analysis which hindered using potential valuable findings. Therefore, oral audio recorded consent or electronic consent would be beneficial for future studies whenever possible.

Joint and group interviews were conducted in two instances where the patient and another FC attended and contributed to the interview. This would have had impact on FCs' views and/or the dominance over the interview participation. However, I have only considered FC's narratives and used the reflective questions and summarising to confirm my interpretations. I also tried to balance asking questions when two FCs were interviewed together.

Time constrains in data collection was a challenge and could be a limitation in achieving theoretical saturation. However, the developed theory identified various perspectives and situations of FCs using the iterative process of data collection and analysis where ideas from one interview informed other interviews. Although efforts were done to include male and female FCs that would facilitate exploring varied support experiences and help in theoretical saturation, the present sample included more female participants. However, it is congruent with the national figures of FCs female/male percentage (80% / 18%, respectively) (Carers UK, 2022).

My personal experience as a secondary FC, tacit knowledge and professional experience as HCP would have influenced my approach to the study. However, determining the potential bias of my views and experiences at early stage helped me realise my position and be open to others' experiences and accept possible changes in my perspective. On the other hand, this personal and professional experiences equipped me with the necessary preparation for exploring FCs' support experiences and establishing a common ground with FCs participated in this study.

7.5.3. Methodological issues

Using grounded theory approach enabled in depth and flexible exploration of the FCs' experiences and developing a theory that described their experiences. The developed theory was presented and discussed in relation to other theoretical interpretations and models in caregiving literature. Although the grounded theory had a structured approach for application in research, it is argued that its evaluative criteria are less clear (Watling and Lingard, 2012). Therefore, the used framework for assessing the quality of this study facilitated its comprehensive evaluation as mentioned earlier in this section. However, the theory itself would be assessed by the contextualisation and saturation of the data that represented the variabilities in experiences and meanings attached to the phenomena under investigation (Foley and Timonen, 2015). The present theory was developed through interpreting a varied sample of FCs and their social characteristics and context was described to enable the potential users of the theory to determine its fit to their practice (Appendix 9.). The data was collected through iterative interviews until no new data or categories properties could be identified further which enhanced capturing different perspectives about the chaotic caregiving experiences and interactions with formal support. Charmaz (2014) identified four criteria for grounded theory evaluation included credibility, originality, resonance, and usefulness. Credibility refers to the provision of richness data that illustrate the different aspects of proposed theory and the relationships existed (Charmaz, 2014, Watling and Lingard, 2012). This was established in the present theory through a detailed explanation of how the data was collected and

analysed as illustrated in methodology chapter. Furthermore, the theory was supported by a wide range of direct participants quotes which illustrated the presented claims and relationships between different theoretical categories.

Originality refers to the new insight, understanding and social significance that is offered by the developed theory (Charmaz, 2014, Watling and Lingard, 2012). The present theory illuminated the different aspects of disruption felt throughout EoL caregiving journey and the experiences of formal support. This would add to the existing theoretical models and interpretations that explored caregiving process and coping in a general perspective. The present theory also provided insight to potential social policy implications in Section 7.4.1.

Resonance of the grounded theory refers to the extent to which the theoretical categories are full developed, reflected the experiences of the people involved and being understandable to them (Charmaz, 2014, Watling and Lingard, 2012). The wealth of data collected allowed for exploring and describing the different properties of theoretical categories. Similarly, informal member checking through interview debriefing and summarising helped to explore the relevance of data to FCs' experience and meanings.

The usefulness of the grounded theory' is described as the ability of the developed theory to offer practical solutions and suggestions for improvement of people experiences and provide direction to future research (Charmaz, 2014, Watling and Lingard, 2012). The present

theory was translated into possible recommendations for improving the healthcare practice and FCs' support. It also highlighted areas that needed further exploration in research in Sections 7.4.2-3.

Lastly, the present theory was developed considering CGT traditions. Thus, it would only be applied within the social context of this sample of FCs and the interview context. Therefore, it is considered as one interpretation of the reality that conform with interpretive paradigm assumptions (Horne, 2011).

7.6. Concluding thoughts

This study explored FCs of PwC experiences of EoLC at home through a grounded theory approach. A theory was developed which revealed that FCs engaged in a process of facing a state of chaos while dealing with PwC's terminal illness and caregiving. FCs tried to adapt to this disruption through their own ways; however, their interaction with formal support either reduced or exacerbated this sense of chaos. A sense of reward or guilt and regret was experienced through this process of **"Facing the caregiving chaos"**, which shaped FCs long lasting experiences and memories.

This PhD study provided useful recommendations for social policy change to support FCs during EoL caregiving such as a supporting work policy and proper social care provision. This study indicated the need for a review of healthcare regulations regarding EoL support at home such as pain control and services accessibility that implicitly affected FCs' ability to cope with caregiving.

The study revealed the need for investing in HCPs' training regarding palliative care provision, communication skills and the understanding of psychodynamics of caregiving process. Creation of caregiving friendly communities through caregiving awareness initiatives would contribute to establishment of empowering environment for EoL caregiving at home. Future research is needed for further examining the relationships existed between various components of the present theory among other population and disease conditions, using larger sample to allow for informative comparisons. This would help developing individualised supportive interventions.

To conclude, this piece of research was intended to portray the current state of FCs' experiences of EoL caregiving and formal support and addressing the current knowledge gaps. However, there is more to be explored and researched in this area of research.

REFERENCES

Abernethy, A., Currow, d., Fazekas, b., Luszcz, m., Wheeler, J.,and Kuchibhatla, M. (2008). Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. *Supportive care in cancer,* 16, 585-597.

Adejoh, S., Boele, F., Akeju, D., Dandadzi, A., Nabirye, E., Namisango, E., Namukwaya, E., Ebenso, B., Nkhoma, K. and Allsop, M. (2021). The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: a multi-country qualitative study. Palliat med, 35(3): 552-562.

Alam, S., Hannon, B. and Zimmermann, C. (2020). Palliative Care for Family Caregivers. Journal of clinical oncology, 38(9): 926-936.

Alemu, G., Stevens, B., Ross, P. and Chandler, J. (2017). The Use of a Constructivist Grounded Theory Method to Explore the Role of Socially-Constructed Metadata (Web 2.0) Approaches. Qualitative and Quantitative Methods in Libraries, 4(3), 517-540.

Alvariza, A., Häger-tibell, L., Holm, M., Steineck, G. and Kreicbergs, U. (2020). Increasing preparedness for caregiving and death in family caregivers of patients with severe illness who are cared for at home – study protocol for a web-based intervention. BMC Palliative Care, 19(1): 33.

American Psychological Association. (2020). How caregiving is defined [Online]. USA: American Psychological Association . Available at :

https://www.apa.org/pi/about/publications/caregivers/research/methods/definition [Accessed: 20-05 2023].

Andershed, B. and Ternestedt, B. (1998). Involvement of relatives in the care of the dying in different care cultures: involvement in the dark or in the light? *Cancer Nursing,* 21(2), 106-111.

Anderson, E. and White, K. (2017). “It Has Changed My Life”: An Exploration of Caregiver Experiences in Serious Illness. American Journal of Hospice and Palliative Medicine®, 35(2): 266-274.

Antwi, S. and Kasim, H. (2015). Qualitative and Quantitative Research Paradigms in Business Research: A Philosophical Reflection. *European Journal of Business and Management*, 7, 217-225

Aranda, S. and Peerson, A. (2001). Caregiving in advanced cancer: Lay decision making. *Journal of Palliative Care,* 17(4), 270-276.

Arber, A., Hutson, N., De Vries, K. and Guerrero, D. (2013). Finding the right kind of support: A study of carers of those with a primary malignant brain tumour. *European Journal of Oncology Nursing,* 17, 52-58.

Arias Rojas, M. and García-vivar, C.(2015). The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers. *Investigación y educación en enfermería,* 33, 482-491.

Avati, A., Jung, K., Harman, S., Downing, L., NG, A. and SHAH, N. H. (2018). Improving palliative care with deep learning. BMC Medical Informatics and Decision Making, 18(Suppl 4): 122.

Bainbridge, D. and Seow, H. (2018). Palliative care experience in the last 3 months of life: A quantitative comparison of care provided in residential hospices, hospitals, and the home from the perspectives of bereaved caregivers. *American Journal of Hospice & Palliative Medicine*, 35, 456-463.

Bannon, F., Cairnduff, V., Fitzpatrick, D., Blaney, J., Gomes, B., Gavin, A. and Donnelly, C. (2018). Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study. *Palliative & Supportive Care*, 16, 749-755.

Barlund, A., André, B., Sand, K. and Brenne, A. T. (2021). A qualitative study of bereaved family caregivers: feeling of security, facilitators and barriers for rural home care and death for persons with advanced cancer. BMC Palliat Care, 20(1): 7.

Barrett, A., Kajamaa, A. and Johnston, J. (2020). How to … be reflexive when conducting qualitative research. *The clinical teacher*, 17, 9-12.

Bastawrous, M. (2013). Caregiver burden—A critical discussion. International journal of nursing studies, 50(3): 431-441.

Batalini, F., Gomes, M., Fábio I ., Kuwae, F., Macanhan, G. and Pereira, J. (2017). Cancer complaints: The profile of patients from the emergency department of a Brazilian oncology teaching hospital. *F1000Res,* 6, 1919.

Beach, M., Sugarman, J., Johnson, R., Arbelaez, J., Duggan, P., and Cooper, L. (2005). Do patients treated with dignity report higher

satisfaction, adherence, and receipt of preventive care? *Annals of family medicine*, 3(4):331-8.

Bearman, M. and Dawson, P. (2013). Qualitative synthesis and systematic review in health professions education. *Medical Education* 47, 252-260.

Bee, P., Barnes, P. and Luker, K. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. Journal of Clinical Nursing, 18, 1379-1393.

Bell, C., Somogyi-zalud, E. and Masaki, K. (2010). Factors associated with congruence between preferred and actual place of death. *J Pain Symptom Manage,* 39(3): 591-604.

Benedict, C., Hahn, A., Diefenbach, M. and Ford, J. (2019). Recruitment via social media: advantages and potential biases. *Digit Health,* 5, 2055207619867223.

Bentley, B. and O'connor, M. (2015). Conducting research interviews with bereaved family carers: when do we ask? *Journal of palliative medicine* 18, 241-245.

Beth, H. (2018). Meeting the needs of people at the end of life.*Nursing standrads* 33(1) 59-65.

Biggs, A., Brough, P. and Drummond, S. (2017). Lazarus and Folkman's psychological stress and coping theory. *The handbook of stress and health: A guide to research and practice.* Hoboken, NJ, US: Wiley Blackwell.

Bijnsdorp, F., Onwuteaka-Philipsen, B., Boot, C., Van Der Beek, A. and Pasman, H. R. (2022). Caregiver’s burden at the end of life of their

loved one: insights from a longitudinal qualitative study among working family caregivers. BMC Palliative Care, 21(1):142.

Bilgin, A. and Ozdemir, L. (2022). Interventions to Improve the Preparedness to Care for Family Caregivers of Cancer Patients: A Systematic Review and Meta-analysis. Cancer Nurs, 45(3): E689-e705.

Blignault, I. and Ritchie, J. (2009). Revealing the wood and the trees: reporting qualitative research. *Health Promotion Journal of Australia,* 20, 140-145.

Bolderston, A. (2012). Conducting a Research Interview. *J Med Imaging Radiat Sci,* 43, 66-76.

Bouchard, E., Prince, M., Mccarty, C., Vincent, P., Patel, H., LaValley, S., Collins, R. L., Sahler, O. J., Krenz, T. and Kelly, K. (2023). Understanding social network support, composition, and structure among cancer caregivers. Psycho-Oncology, 32(3): 408-417.

Bowers, B. (1987). Intergenerational caregiving: adult caregivers and their aging parents. *Advances in Nursing Science,* 9(2):20-31.

Bowers, B. (1988). Family perceptions of care in a nursing home. *Gerontologist,* 28(3): 361-8.

Bradley, E., Curry, L. and Devers, K. (2007). Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory. *Health services research,* 42(4):1758-1772.

Brashers, D. (2001). Communication and Uncertainty Management. *Journal of communication,* 51(3): 477-497.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology,* 3(2): 77-101.

Bray, F., Ferlay, J., Soerjomataram , I., Siegel , R., Torre, L. and Jemal , A. (2018). Global canncer statistics 2018: Globocan estimates of incidence and moratlity worldwide for 36 in 185 countries *CA CANCER J CLIN,* 68(6) 394-424.

Brazil, K., Bainbridge, D. and Rodriguez, C. (2010). The stress process in palliative cancer care: A qualitative study on informal caregiving and its implication for the delivery of care. *American Journal of Hospice & Palliative Medicine,* 27(2): 111-116.

Brobäck, G. and Berterö, C. (2003). How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care,* 12(4): 339-346.

Broom, A. and Willis, E. (2007). Competing paradigms and health research. *Researching health: qualitative, quantitative and mixed methods*, 16-31.

Brown, R. and Brown, S. (2014). Informal Caregiving: A Reappraisal of Effects on Caregivers. *Social Issues and Policy Review,* 8(1):74-102.

Calanzani, N., Koffman, J. and Higginson, I. (2013). *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK*.

Cambridge University Press & Assessment. (2023). Meaning of chaos in English in: Cambridge dictionary [Online]. UK: Cambridge University Press & Assessment. Available at : https://dictionary.cambridge.org/dictionary/english/chaos [Accessed 10-03-2023 2023].

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D. and Walker, K. (2020). Purposive sampling:

complex or simple? Research case examples. *Journal of research in nursing,* 25(8):652-661.

Cancer Research UK. (2020). Stages of Cancer [Online]. Available at: https://www.cancerresearchuk.org/about-cancer/what-is-cancer/stages-of-cancer [Accessed 16-11-2022 2022].

Carbonneau, H., Caron, C. and Desrosiers, J.(2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia (London, England),* 9(3): 327-353.

Carers UK. (2022). State of Caring 2022.UK:CarersUK. Available at: https://www.carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf [Accessed 21-06-2023]

Carersweek.(2022). Making Caring Visible, valued, and Supported.UK:Carersweek. Available at: https://www.carersweek.org/media/qf0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf. [Accessed 21-06-2023].

Carroll, C. and Booth, A.(2015). Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? *Research Synthesis Methods,* 6(2):149-154.

Carter, C and Notter,J. (2022). COVID-19 : a critical care textbook. London: Elsevier.

Caswell, G., Pollock, K., Harwood, R. and Porock, D. (2015). Communication between family carers and health professionals about

end-of-life care for older people in the acute hospital setting: a qualitative study. BMC Palliative Care, 14: 35.

Centre for Reviews and Dissemination, University of York. (2018). International Prospective Register of Systematic Reviews (PROSPERO) [Online]. Centre for Reviews and Dissemination, University of York Available at: https://www.crd.york.ac.uk/prospero/ [Accessed 07-07-2023].

Chalmers, A. (2013). *What is this thing called science?4th ed.*Maidenhead : Open University Press.

Chapple, A., Evans, J., Mcpherson, A. and Payne, S. (2011). Patients with pancreatic cancer and relatives talk about preferred place of death and what influenced their preferences: a qualitative study. *BMJ Support Palliat Care,* 1(3): 291-5.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods, Thousand Oaks, CA: Sage.

Charmaz , K. (2001). *Qualitative interviewing and grounded theory analysis,* Thousand Oaks, CA: Sage.

Charmaz, K. (2006). Constructing grounded theory : a practical guide through qualitative analysis. London. : Sage Publications.

Charmaz, K. (2014). Constructing grounded theory. London : SAGE.

Charmaz, K. (2017). Special Invited Paper: Continuities, Contradictions, and Critical Inquiry in Grounded Theory. *International Journal of Qualitative Methods,* 16(1): 1609406917719350.

Cheng, Q., Xu, B., NG, M., Zheng, H. and So, W. (2022). Needs assessment instruments for family caregivers of cancer patients receiving palliative care: a systematic review. Supportive care in cancer, 30(10): 8441-8453.

Cobb, S.(1982). An approach to the relationship between social networks, the sense of social and health. The Sunbelt Social Networks Conference.

Cohen , D. and Crabtree , B. (2006). *Qualitative Research Guidelines Project* [Online]. Princeton: Robert Wood Johnson Foundation. Available: http://www.qualres.org/HomeRefl-3703.html [Accessed June 2019].

Cohen, D. and Crabtree, B. (2008). Evaluative criteria for qualitative research in health care: controversies and recommendations. *Ann Fam Med,* 6(4): 331-9.

Collins, L. and Swartz, K. (2011). Caregiver care. *American Family Physician,* 83(11): 1309-1317.

Colombo, F., Llena-nozal, A., Mercier, J. and Tjadens, F. (2011). *Help Wanted?: Providing and Paying for Long-Term Care,,* Paris, OECD Health Policy Studies,OECD Publishing.

Comstock Barker, P. and Scherer, J. S. (2017). Illness Trajectories: Description and Clinical Use #326. Journal of palliative medicine, 20(4): 426-427.

Connelly, L. (2016). Trustworthiness in Qualitative Research. *Medsurg Nurs,* 25(6): 435-6.

Cooke, B., Rossmann, M., Mccubbin, H. and Patterson, J. (1988). Examining the Definition and Assessment of Social Support: A Resource for Individuals and Families. *Family Relations,* 37, 211-216.

Cooley, C. (1915). *Social organization a study of the larger mind.* New York : C. Scribner's sons.

Cooper, C. and Quick, J. (2017). *The Handbook of Stress and Health : A Guide to Research and Practice.* Newark, United States:John Wiley & Sons, Incorporated.

Corbin, J.(1998). The Corbin and Strauss Chronic Illness Trajectory Model: An Update. *Research and theory for nursing practice,* 12(1):33.

Coventry, A., Mcinnes, E., Resenberg, J. and Ford, R. (2017). End-of-life-care in the ICU: a qualitative meta-synthesis investigating the experiences and perceptions of the patients family. *Australian Critical Care,* 30(2): 113.

Coyne, I. (1997). Sampling in qualitative research. Purposeful and theoretical sampling merging or clear boundaries? *Journal of advanced nursing,* 26(3) 623-630.

Creswell, J and Poth, C.(2018a). *Qualitative inquiry & research design : choosing among five approaches. 4th ed., International Student ed.* London: SAGE Publications.

Creswell, J and *Creswell D*. (2018b). *Research design : qualitative, quantitative, and mixed methods approaches.5th ed. International student edition. Los Angeles*: Sage Publications.

Critical Appraisal Skills Programme (CASP). (2018). Critical Appraisal Skills Programme:Making sense of evidence about clinical effectiveness.10 Questions to help you making sense of quaitative research [Online]. Available at : https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf [Accessed 3 March 2019].

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*.Sage Publications.

Cypress, B. (2017). Rigor or Reliability and Validity in Qualitative Research: Perspectives, Strategies, Reconceptualization, and Recommendations. *Dimensions of critical care nursing,* 36(4): 253-263.

Decarlo, M. (2018). *Scientific Inquiry in Social Work,* Place of publication not identified, Place of publication not identified: Open Social Work Education.

Del Rio Lozano, M., Garcia-Calvente, M., Calle-Romero, J., Machon-Sobrado, M. and Larranaga-Padilla, I. (2017). Health-related quality of life in Spanish informal caregivers: Gender differences and support received. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation,* 26(12): 3227-3238.

Department of Health.(2008). End of Life Care Strategy:promoting high quality care for all adults at the end of life. London:Department of Health.

Department of Health and Social Care.(2018). How can we improve support for carers?: Government response to the 2016 carers call for evidence.UK:Department of Health and Social Care.

Department of Health and Social Care. (2023). Press release: Cancer survival rates improve by almost 10% [Online]. UK government, Available: https://www.gov.uk/government/news/cancer-survival-rates-improve-by-almost-10#:~:text=NHS%20England%20has%20published%20a,risen%209%25%20to%2074.6%25. [Accessed 18-05-2023 2023].

Department of Health and social Care (2018). Carers Action Plan 2018 - 2020 Supporting carers today. UK:Department of Health and Social Care.

Department of Health and Social Care.(2022). National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. UK: Department of Health&social care.

Dionne-Odom, J., Demark-Wahnefried, W., Taylor, R., Rocque, G., Azuero, A., Acemgil, A., Martin, M., Astin, M., Ejem, D., Kvale, E., Heaton, K., Pisu, M., Partridge, E. and Bakitas, M.(2017). The self-care practices of family caregivers of persons with poor prognosis cancer: differences by varying levels of caregiver well-being and preparedness. *Support Care Cancer,* 25, 2437-2444.

Dixon Josie , K., Matosevic ., Clark M and Knapp, M. (2015). Equity in the Provision of Palliative Care in the UK: Review of Evidence. London: The Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science.

Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J. and Carter, Y. (2008). Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine,* 22(2): 153-71.

Dodgson, J. (2019). Reflexivity in Qualitative Research. *Journal of human lactation,* 35(2): 220-222.

Doherty, L., Fitzsimons, D. and Mcilfatrick, S. (2016). Carers' needs in advanced heart failure: A systematic narrative review. European Journal of Cardiovascular Nursing, 15(4), 203-212.

DuBenske, L., Wen, K., Gustafson, D., Guarnaccia, C., Cleary, J., Dinauer, S. and Mctavish, F. (2008). Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliative and Supportive Care,* 6(3): 265-272.

Duffy, K., Ferguson, C. and Watson, H. (2004). Data collecting in grounded theory--some practical issues. *Nurse researcher,* 11(4): 67.

Duggleby, W., Tycholiz, J., Holtslander, L., Hudson, P., Nekolaichuk, C., Mirhosseini, M., Parmar, J., Chambers, T., Alook, A. and Swindle, J. (2017). A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliative Medicine,* 31(7): 602-616.

Duggleby, W., Penz, K., Leipert, B., Wilson, D., Goodridge, D. and Williams, A. (2011) . 'I am part of the community but...' The changing context of rural living for persons with advanced cancer and their families. *Rural & Remote Health,* 11(3):1733-1733.

Duggleby, W., Penz, K., Goodridge, D., Wilson, D., Leipert, B., Berry, P., Keall, S. and Justice, C. (2010). The transition experience of rural older persons with advanced cancer and their families: a grounded theory study. *BMC Palliative Care,* 9(1): 1-9.

Dumont, I., Dumont, S. and Mongeau, S. (2008). End-of-life care and the grieving process: family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qualitative health research,* 18(8): 1049-1061.

Dunlop, M. (1986). Is a science of caring possible? *Journal of Advanced Nursing,* 11(6): 661-670.

Ellershaw, J. and Ward, C. (2003). Care Of The Dying Patient: The Last Hours Or Days Of Life. *BMJ (Clinical Research Edition).* 326(7379): 30-34.

Elliott, V. (2018). Thinking about the Coding Process in Qualitative Data Analysis. *Qualitative report.* 23(11): 2850 - 2861.

Emerson, E., Fortune, N., Llewellyn, G. and Stancliffe, R. (2021). Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study. Disability and health journal, 14(1): 100965-100965.

Engward, H. and Davis, G. (2015). Being reflexive in qualitative grounded theory: discussion and application of a model of reflexivity. *Journal of advanced nursing,* 71(7):1530-1538.

Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., Rob, G., Beynon, T., Higginson, I. and Harding, R. (2012). Adjusting to the

caregiving role: the importance of coping and support. *International Journal of Palliative Nursing,* 18(11):541-545.

Etkind, S., Lovell, N., Nicholson, C., Higginson, I. and Murtagh, F. (2019). Finding a 'new normal' following acute illness: A qualitative study of influences on frail older people's care preferences. Palliat Med, 33(3), 301-311.

Exley, C. and Tyrer, F. (2005). Bereaved carers' views of a hospice at home service. *International Journal of Palliative Nursing,* 11(5): 242-246.

Faraci, P. and Bottaro, R. (2022). Association Between Perceived Social Support, Illness Perception, Life Orientation, Life Satisfaction, and Quality of Life Within a Sample of Cancer Patients/Asociacion entre el apoyo social percibido, la percepcion de la enfermedad, la orientacion a la vida, la satisfaccion con la vida y la calidad de vida dentro de una muestra de pacientes con cancer. International journal of psychological research, 15(1): 9-19.

Garrard, E., Fennell, K. and Wilson, C., (2017). 'We're completely back to normal, but I'd say it's a new normal': a qualitative exploration of adaptive functioning in rural families following a parental cancer diagnosis. Supportive Care in Cancer, 25(11), 3561-3568.

Fisher, C., Wright, K., Hampton, C., Vasquez, T., Kastrinos, A., Applebaum, A., Sae-Hau, M., Weiss, E., Lincoln, G. and Bylund, C. (2021). Blood cancer caregiving during COVID-19: understanding caregivers' needs. *Translational Behavioral Medicine,* 11(5): 1187-1197.

Flemming, K., Atkin, K., Ward, C. and Watt, I. (2019). Adult family carers' perceptions of their educational needs when providing end-of-life care : a systematic review of qualitative research. AMRC Open Research, 1(2): 1-26.

Foley, G. and Timonen, V. (2015). Using Grounded Theory Method to Capture and Analyze Health Care Experiences. *Health Services Research,* 50(4): 1195-1210.

Foley, N., Clark, H., Kennedy S ., Roberts, N. and Francis-Devine, B. (2022). Informal Carers. UK: House of Commons.

Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G. and Todd, C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine,* 24(6): 594-607.

Funk, L., Allan, d. and Stajduhar, K. (2009). Palliative family caregivers' accounts of health care experiences: the importance of "security". *Palliative & supportive care,* 7(4): 435-447.

Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L. and Gott, M. (2013). Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. Palliative Medicine, 28(5): 375-390.

Gardiner, C., Gott, M. and Ingleton, C. (2012). Factors supporting good partnership working between generalist and specialist palliative care services: a systematic review. *British journal of general practice,* 62(598): e353-e362.

Garratt, K., Kirk-Wade, E., Harker, R., and Mirza-Davies, J. (2023). The NHS workforce in England. UK: House of commons.

General Medical Council. (2010). Treatment and care towards the end of life: good practice in decision making.UK: General Medical Council.

Ghezeljeh, T. and Emami, A. (2009). Grounded theory: methodology and philosophical perspective. *Nurse Res,* 17(1): 15-23.

Gilbert, E., Ussher, J., Perz, J., Hobbs, K. and Kirsten, L. (2010). Positive and Negative Interactions With Health Professionals: A Qualitative Investigation of the Experiences of Informal Cancer Carers. *Cancer Nursing,* 33(6): E1-E9.

Gill, P., Burnard, P., Stewart, K., Treasure, E. and Chadwick, B. (2008). Analysing and presenting qualitative data. *British dental journal,* 204(8): 429-432.

Girgis, A. and Lambert, S. (2009). Caregivers of Cancer Survivors: The State of the Field. *Cancer Forum,* 33(3): 168-171.

Girgis, A., Lambert, S., Johnson, C., Waller, A. and Currow, D. (2012). Physical, Psychosocial, Relationship, and Economic Burden of Caring for People With Cancer: A Review. *Journal of Oncology Practice,* 9(4):197-202.

Given, B., Given, C. and Kozachik, S.(2001). Family Support in Advanced Cancer. *CA: A Cancer Journal for Clinicians,* 51(4): 213-231.

Glaser, B. and Strauss, A. (1967). *The discovery of grounded theory : strategies for qualitative research.* New York : Aldine.

Glaser, B. (1978). *Theoretical sensitivity : advances in the methodology of grounded theory.* Mill Valley, Calif. : Sociology Press.

Glaser, B. (1998). *Doing grounded theory : issues and discussions*, Mill Valley, CA : Sociology Press.

Glaser, B. and Strauss, A. (1965). Awareness of dying. Chicago: Aldine.

Gomes, B., Calanzani, N. and Higginson, I. (2014). Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers. *JAMA: Journal of the American Medical Association,* 311(10): 1060-1061.

Gonella, S., Basso, I., De Marinis, M., Campagna, S. and Di Giulio, P. (2019). Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings. *Palliat Med,* 33(6): 589-606.

Gorman, J., Roberts, S., Dominick, S., Malcarne, V., Dietz, A. and Su, H. (2014). A Diversified Recruitment Approach Incorporating Social Media Leads to Research Participation Among Young Adult-Aged Female Cancer Survivors. *J Adolesc Young Adult Oncol,* 3(2): 59-65.

Gott, M. Stosz L and Alaszewski A. (2008). At odds with the End of Life Care Strategy. *Nurs Older People,* 20(7):24-7.

Gotze, H., Brahler, E., Gansera, L., Schnabel, A., Gottschalk-Fleischer, A. and Kohler, N. (2018). Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *Eur J Cancer Care (Engl),* 27(2): e12606.

Goulding, C. (2005). Grounded theory, ethnography and phenomenology: A comparative analysis of three qualitative strategies for marketing research. *European Journal of Marketing,* 39(3/4): 294-308.

Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne, S. and Todd, C. (2009). Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine,* 23(4): 339-344.

Grant, M. and Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. Health information and libraries journal, 26(2): 91-108.

Gray-Burrows, K., Willis, T., Foy, R., Rathfelder, M., Bland, P., Chin, A., Hodgson, S., Ibegbuna, G., Prestwich, G., Samuel, K., Wood, L., Yaqoob, F. and Mceachan, R. (2018). Role of patient and public involvement in implementation research: a consensus study. *BMJ Quality &Safety,* 27(10): 858-864.

Gray, B. (2011). England's Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices. The Commonwealth Fund.

Grbich, C., Maddocks, I. and Parker, D. (2001). Family caregivers, their needs, and home-based palliative cancer services. *Journal of Family Studies,* 7(2): 171-188.

Griffin, A. (1983). A philosophical analysis of caring in nursing. *Journal of advanced nursing,* 8(4): 289-295.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C., Willan, A., Viola, R., Coristine, M., Janz, T. and Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. Canadian Medical Association Journal, 170(12): 1795-801.

Guerriere, D., Husain, A., Zagorski, B., Marshall, D., Seow, H., Brazil, K., Kennedy, J., Burns, S., Brooks, H. and Coyte, P. (2016). Predictors of caregiver burden across the home-based palliative care trajectory in Ontario, Canada. *Health & Social Care in the Community,* 24(4): 428-438.

Guo, J.W., Reblin, M., Tay, D., Ellington, L., Beck, A. and Cloyes, K. (2021). Patterns of stress and support in social support networks of in-home hospice cancer family caregivers. J Soc Pers Relat, 38(11): 3121-3141.

Gwilliam, B., Keeley, V., Todd, C., Roberts, C., Gittins, M., Kelly, L., Barclay, S. and Stone, P. (2013). Prognosticating in patients with advanced cancer—observational study comparing the accuracy of clinicians' and patients' estimates of survival. Annals of oncology, 24(2), 482-488.

Gysels, M. and Higginson, I. (2009). Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliat Support Care,* 7(2): 153-62.

Hadi, M. and José Closs, S. (2016). Ensuring rigour and trustworthiness of qualitative research in clinical pharmacy. *International journal of clinical pharmacy,* 38(3): 641-646.

Haigh, C. and Witham, G. (2015). *Distress protocol for data collection* [Online]. Manchester Metropolitan Univeristy Available at : https://www2.mmu.ac.uk/media/mmuacuk/content/documents/rke/Advisory-Distress-Protocol.pdf [Accessed 17 May 2019].

Hansford, P. and Meehan, H. (2007). Gold Standards Framework: improving community care. *End of Life Care,* 1(3): 56-61.

Harding, R. (2013). Informal caregivers in home palliative care. *Progress in Palliative Care,* 21(4): 229-231.

Harding, R., Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., George, R., Beynon, T., Higginson, I. (2012). What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer,* 20(9): 1975-1982.

Haun, M., Estel, S., Rücker, G., Friederich, H., Villalobos, M., Thomas, M. and Hartmann, M. (2017). Early palliative care for adults with advanced cancer. *Cochrane Database of Systematic Reviews,(6)*.

Hauser, J. and Kramer, B. (2004). Family caregivers in palliative care. *Clinics in geriatric medicine,* 20(4): 671-688.

Higgins, J. and Green, S. (2008). *Cochrane handbook for systematic reviews of interventions .* Chichester, Chichester : Wiley-Blackwell.

Higginson, I.(1997).Palliative and Terminal Care. Available at : https://www.birmingham.ac.uk/Documents/college-mds/haps/projects/HCNA/004HCNAchap4.pdf [Accessed 23-06-2023]

Holloway, I. and Galvin, K. (2016). *Qualitative Research in Nursing and Healthcare.4th ed.* Hoboken,UK, John Wiley & Sons, Incorporated.

Holm, M., Henriksson, A., Carlander, I., Wengström, Y. and Öhlen, J. (2015). Preparing for family caregiving in specialized palliative home care: An ongoing process. Palliative & Supportive Care, 13(3):767-775.

Holmberg, L. (2006a). Communication in Action Between Family Caregivers and a Palliative Home Care Team. *Journal of Hospice & Palliative Nursing,* 8(5): 276-287.

Holmberg, L. (2006b). Communication in palliative home care: a dying son and his mother. *Journal of Hospice & Palliative Nursing,* 8(1): 15-24.

Horne, G. (2011). Maintaining integrity in the face of death: the views and experiences of people affected by lung cancer in discussing preferences and wishes for end of life care. Doctoral thesis, University of Nottingham.

House, J., (1981). *Work stress and social support.*Reading;Addison-Wesley Pub.

Houses of Parliament. (2018). Unpaid care. London: Houses of Parlaiment. Available at : https://researchbriefings.files.parliament.uk/documents/POST-PN-0582/POST-PN-0582.pdf. [Accessed 23 June 2023]

Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing,* 10(2) 58-65.

Hudson, P. (2013). Improving support for family carers: key implications for research, policy and practice. Palliative medicine 27(7): 581–582.

Hudson, P., Aranda, S. and Kristjanson, L. (2004). Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. Journal of palliative medicine, 7(1), 19-25.

Hughes, J., Camden, A. and Yangchen, T. (2016). Rethinking and updating demographic questions: Guidance to improve descriptions of research samples. *Psi Chi Journal of Psychological Research,* 21(3): 138-151.

Ipsos MORI and Macmillan Cancer Support.(2011). More than a million; Understanding the UK's Carers of People with cancer - a report by Ipsos Mori for Macmillan Cancer Support[Online]. UK: Macmillan Cancer Support. Available at https://www.macmillan.org.uk/documents/cancerinfo/ifsomeoneelsehascancer/more_than_a_million.pdf [Accessed 07 July 2023]

Jadalla, A., Page, M., Ginex, P., Coleman, M., Vrabel, M. and Bevans, M. (2020). Family Caregiver Strain and Burden: A Systematic Review of Evidence-Based Interventions When Caring for Patients With Cancer. *Clinical journal of oncology nursing,* 24(1): 31-50.

Janghorban, R., Roudsari, R. and Taghipour, A. (2014). Skype interviewing: The new generation of online synchronous interview in

qualitative research. *International journal of qualitative studies on health and well-being,* 9(1): 24152-24152.

Johnston, B., Milligan, S., Foster, C. and Kearney, N. (2012). Self-care and end of life care--patients' and carers' experience a qualitative study utilising serial triangulated interviews. *Supportive Care in Cancer,* 20(8): 1619-1627.

Kanavaki, A., Rushton, A., Klocke, R., Abhishek, A. and Duda, J. (2016). Barriers and facilitators to physical activity in people with hip or knee osteoarthritis: protocol for a systematic review of qualitative evidence. *BMJ open,* 6(11): e012049-e012049.

Kim, Y. and Baek, W. (2022). Caring experiences of family caregivers of patients with pancreatic cancer: an integrative literature review. *Supportive Care in Cancer,* 30(5): 3691-3700.

Kinoshita, H., Maeda, I., Morita, T., Miyashita, M., Yamagishi, A., Shirahige, Y., Takebayashi, T., Yamaguchi, T., Igarashi, A. and Eguchi, K. (2015). Place of death and the differences in patient quality of death and dying and caregiver burden. *Journal of clinical oncology,* 33(4): 357-63.

Kirchhoff, K. and Kehl, K. (2007). Recruiting Participants in End-of-Life Research. *American Journal of Hospice and Palliative Medicine,* 24(6): 515-521.

Klarare, A., Rasmussen, B., Fossum, B., Fürst, C., Hansson, J. and Hagelin, C. (2017). Experiences of security and continuity of care: Patients' and families' narratives about the work of specialized palliative home care teams. Palliative & supportive care, 15(2): 181-189.

Kmetec, S., Fekonja, Z., Kolarič, J. Č., Reljić, N., McCormack, B., Sigurðardóttir, Á. and Lorber, M. (2022). Components for providing person-centred palliative healthcare: An umbrella review. International Journal of Nursing Studies, 125:104111.

Korstjens, I. and Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *The European journal of general practice,* 24(1):120-124.

Krawczyk, M. and Rush, M. (2020). Describing the end-of-life doula role and practices of care: perspectives from four countries. *Palliat Care Soc Pract,* 14: 2632352420973226.

Kristjanson, L. and Aoun, S. (2004). Palliative Care for Families: Remembering the Hidden Patients. *Canadian journal of psychiatry,* 49(6): 359-365.

Kruth, J. (2015). Five qualitative research approaches and their applications in parapsychology 1. *The Journal of Parapsychology,* 79(2): 219-233.

Lambert, S., Harrison, J., Smith, E., Bonevski, B., Carey, M., Lawsin, C., Paul, C. and Girgis, A. (2012). The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Supportive & Palliative Care,* 2(3) 224-30.

Larsson, M., Lee, S., Wilde-Larsson, B., Olsson, C., Bjuresäter, K., Hov, R., Grov, E. and Kennedy, C. (2016). Family carers' preferences for support when caring for a family member at the end of life at home: protocol for an integrative literature review. *International prospective register of systematic reviews*.

Lavallée, J. F., Grogan, S. and Austin, C. (2019). Cancer patients' family members' experiences of the information and support provided by healthcare professionals. The Health Education Journal, 78(4): 416-427.

Lazarus, R., and Folkman S.(1984). *Stress, appraisal, and coping.* New York : Springer.

Lazarus, R. (1991). Emotion and adaptation. Oxford: Oxford University Press.

Lee, H.-T. S., Melia, K., Yao, C.-A., Lin, C.-J., Chiu, T-Y. and Hu, W-Y. (2014). Providing hospice home care to the terminally ill elderly people with cancer in Taiwan: Family experiences and needs. *American Journal of Hospice & Palliative Medicine,* 31(6): 628-635.

Leow, M. and Chan, S. (2017). The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: A qualitative study. *Cancer Nursing,* 40(1): 22-30.

Levers, M.-J D. (2013). Philosophical paradigms, grounded theory, and perspectives on emergence. *Sage Open,* 3:2158244013517243.

Levine, C. (2016). *Carer, Caregiver, What's in a Name?* [Online]. New York, : United Hospital Fund. Available at : https://uhfnyc.org/publications/publication/carer-caregiver-whats-name/ [Accessed 19-05 2023].

Levine, C. and Zuckerman, C. (1999). The Trouble with Families: Toward an Ethic of Accommodation. *Annals of Internal Medicine,* 13(2):148-152.

Li, Q. and Loke, A. (2013). The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research. *Psycho-Oncology,* 22(11): 2399-2407.

Lim, J. and Zebrack, B. (2004). Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health Qual Life Outcomes,* 2(50): 1-9.

Lincoln, Y. and *Guba*, E. (1985). *Naturalistic inquiry.* London : Sage.

Linderholm, M. and Friedrichsen, M. (2010). A desire to be seen: family caregivers' experiences of their caring role in palliative home care. *Cancer nursing,* 33(1): 28-36.

Lipson, J. (1994). Ethical issues in ethnography. *Critical issues in qualitative research methods*, 333-355.

Little, M., Jordens, C., Paul, K., Montgomery, K. and Philipson, B. (2022). Liminality: A major category of the experience of cancer illness. Journal of bioethical inquiry, 19(1), 37-48.

Lockwood, C., Porrit, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., Loveday, H., Carrier, J. and Stannard, D. (2020). Chapter 2: Systematic reviews of qualitative evidence. Joanna Briggs Institute Reviewer's Manual. Adelaide:The Joanna Briggs Institute. Available at https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-03 [Accessed 15 Oct 2023]

Long, H., French, D. and Brooks, J. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal

in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences,* 1(1): 31-42.

Lortet-tieulent, J., Georges, D., Bray, F. and Vaccarella, S. (2020). Profiling global cancer incidence and mortality by socioeconomic development. *Int J Cancer,* 147(11): 3029-3036.

Lovatt, M., Nanton, V., Roberts, J., Ingleton, C., Noble, B., Pitt, E., Seers, K. and Munday, D. (2015). The provision of emotional labour by health care assistants caring for dying cancer patients in the community: a qualitative study into the experiences of health care assistants and bereaved family carers. *Int J Nurs Stud,* 52(1): 271-9.

Luijkx, K. and Schols, J. (2009). Volunteers in palliative care make a difference. *Journal of Palliative Care,* 25(1): 30-39.

Lunney, J., Lynn, J. and Hogan, C. (2002). Profiles of Older Medicare Decedents. *Journal of the American Geriatrics Society (JAGS),* 50(6): 1108-1112.

Lysaght Hurley, S., Strumpf, N., Barg, F. and Ersek, M. (2014). Not quite seamless: transitions between home and inpatient hospice. *J Palliat Med,* 17(4): 428-34.

MacArtney, J., Broom, A., Kirby, E., Good, P., Wootton, J. and Adams, J. (2016). Locating care at the end of life: Burden, vulnerability, and the practical accomplishment of dying. *Sociology of Health & Illness,* 38(3): 479-492.

Macmillan Cancer Support.(2022). Statistics fact sheet [Online]. Macmillan Cancer Support. Available at : https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b

2a629/9468-10061/2022-cancer-statistics-factsheet [Accessed 15 Oct 2023].

Maddalena, V., Bernard, W., Etowa, J., Murdoch, S., Smith, D. and Marsh Jarvis, P. (2010). Cancer care experiences and the use of complementary and alternative medicine at end of life in Nova Scotia's Black Communities. *J Transcult Nurs,* 21(2): 114-22.

Maher, J., Velikova, G. and Betteley, A. (2015). Incurable, but treatable: how to address challenges for an emerging group. *BMJ supportive & palliative care,* 5(4): 322-4.

Maltby, K., Sanderson, C., Lobb, E. and Phillips, J. (2017). Sleep disturbances in caregivers of patients with advanced cancer: A systematic review. *Palliative & supportive care,* 15(1): 125-140.

Marco, D J., Thomas, K., Ivynian, S., Wilding, H., Parker, D., Tieman, J. and Hudson, P. (2022). Family carer needs in advanced disease: systematic review of reviews. *BMJ supportive & palliative care,* 12(2): 132-141.

Marie Curie. (2017). Making every moment count;The state of Fast Track Continuing Healthcare in England. UK: Marie Curie,.

Martín, J., Olano-lizarraga, M. and Saracíbar-Razquin, M. (2016). The experience of family caregivers caring for a terminal patient at home: A research review. *International Journal of Nursing Studies,* 64:1-12.

Martz, K. and Morse, J. (2017). The changing nature of guilt in family caregivers: Living through care transitions of parents at the end of life. *Qualitative Health Research,* 27(7): 1006-1022.

Mason, N. and Hodgkin, S. (2019). Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers. Health & Social Care in the Community, 27(4): 926-935.

Mays, N. and Pope, C. (2000). Assessing quality in qualitative research. *BMJ,* 320(7226): 50-2.

Maz, J. (2013). Employing a grounded theory approach: core characteristics. *British Journal of Cardiac Nursing,* 8(9): 453-458.

McCarthy, E., Phillips, R., Zhong, Z., Drews, R. and Lynn, J. (2000). Dying with Cancer: Patients' Function, Symptoms, and Care Preferences as Death Approaches. *Journal of the American Geriatrics Society (JAGS),* 48(S1): S110-S121.

McCaughan, D., Roman, E., Smith, A., Garry, A., Johnson, M., Patmore, RD., Howard, MR. and Howell, DA. (2019). Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: A qualitative study. *Palliative Medicine,* 33(5): 518-530.

McCosker, H., Barnard, A. and Gerber, R. (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All Participants. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research,* (Vol.2, No.1).

McDonald, J., Mckinlay, E., Keeling, S. & Levack, W. (2016). Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. Journal of Advanced Nursing, 72(9): 2173-2184.

McFadyen, J. and Rankin, J. (2017). The role of gatekeepers in research: learning from reflexivity and reflection. *GSTF Journal of Nursing and Health Care (JNHC),* 4(1).

Meleis, A., Sawyer, L., Im, E., Messias, D. and Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in nursing science,* 23(1): 12-28.

Milberg, A., Olsson, E., Jakobsson, M., Olsson, M. and Friedrichsen, M. (2008). Family members' perceived needs for bereavement follow-up. *Journal of Pain & Symptom Management,* 35(1): 58-69.

Milberg, A. and Strang, P. (2004). Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psycho-Oncology,* 13(9): 605-618.

Milberg, A., Strang, P., Carlsson, M. & Börjesson, S. (2003). Advanced palliative home care: next-of-kin's perspective. Journal of Palliative Medicine, 6(5), 749-756.

Miller, M. (2018). *Cancer.*New York : Momentum Press.

Mills, J., Bonner, A. and Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods,* 5(1): 25-35.

Miranda do Vale, J., Marques Neto, A., Silva dos santos, L. and de Santana, M. (2019). Self-care of the caregiver of the sick in adequate palliative oncological home care. *Journal of Nursing UFPE / Revista de Enfermagem UFPE,* 13, 6-15.

Moback, B., Gerrard, R., Campbell, J., Taylor, L., Minton, O. and Stone, P. (2011). Evaluating a fast-track discharge service for patients wishing to die at home. International journal of palliative nursing, 17(10), 501-506.

Mok, E., Chan, F., Chan, V. and Yeung, E. (2003). Family Experience Caring for Terminally Ill Patients With Cancer in Hong Kong. *Cancer Nursing,* 26(4): 267-275.

Molassiotis, A. and Wang, M. (2022). Understanding and Supporting Informal Cancer Caregivers. Curr Treat Options Oncol, 23(4):494-513.

Montgomery, P. and Bailey, P. (2007). Field Notes and Theoretical Memos in Grounded Theory. *Western Journal of Nursing Research,* 29(1): 65-79.

Morris, S., King, C., Turner, M. and Payne, S. (2015). Family carers providing support to a person dying in the home setting: A narrative literature review. Palliative medicine, 29(6):487-95.

Morris, S., Payne, S., Ockenden, N. and Hill, M. (2017). Hospice volunteers: bridging the gap to the community?.*Health & Social Care in the Community,* 25(6): 1704-1713.

Morse, J. (2000). Determining Sample Size. *Qualitative Health Research,* 10(1): 3-5.

Muntanyola Saura, D. and Romero Balsas, P. (2013). Interviewing and surveying over the phone: a reflexive account of a research on parenting. *Quality & quantity,* 48: 2615-2630.

Murray, S., Kendall, M., Boyd, K. and Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ,* 330(7498): 1007-1011.

Murrell, A., Rimmer, B., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T. and Sharp, L. (2023). The Nature and Quality of Support from Informal Networks for Informal Caregivers of Low-Grade Glioma Patients: A Qualitative Analysis within the Ways Ahead Study. European Journal of Cancer Care, 2023: 4149412.

Myers, M. (2013). *Qualitative research in business & management.* London: Sage.

Namba, M., Morita, T., Imura, C., Kiyohara, E., Ishikawa, S. and Hirai, K. (2007). Terminal delirium: families' experience. *Palliative Medicine,* 21(7): 587-594.

Nathan, D. (2014). *Quality end of life care for people with dementia: The views and experiences of family carers.* Doctoral thesis, University College London.

National Audit Office. (2008). *Patient and Carer experiences regarding End of Life Care in England Final Report* [Online]. National Audit Office Available at : https://www.nao.org.uk/wp-content/uploads/2008/11/07081043_patientcarersurvey.pdf [Accessed April 2019].

National Institute For Clinical Excellence (NICE). (2004). Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer[online]. London: National Institute for Clinical Excellence. Available at:

https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005 [Accessed 06 July 2023].

Newland E. (2021). *What is a death doula?* [Online]. UK: Marie Curie. Available at : https://www.mariecurie.org.uk/talkabout/articles/what-is-a-death-doula/288358 [Accessed 15 May 2023].

NHS. (2022). Cancer incidence and mortality [Online]. NHS. Available at: https://www.cancerdata.nhs.uk/incidence_and_mortality [Accessed 24 June2023].

NICE.(2012). Palliative care for adults: strong opioids for pain relief. UK: National Institute for Health and Care Excellence [online]. Available at: https://www.nice.org.uk/guidance/cg140/resources/palliative-care-for-adults-strong-opioids-for-pain-relief-pdf-35109564116677 [Accessed 06 July 2023].

NICE. (2015a). Care of dying adults in the last days of life[online]. UK: National Institute for Health and Care Excellence (NICE). Available at: https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-1837387324357 [Accessed 06 July 2023].

NICE (2015b). Transition between inpatient hospital settings and community or care home settings for adults with social care needs[online]. UK: National Institue for Health and Care Excellence (NICE). Available at:

https://www.nice.org.uk/guidance/ng27/resources/transition-between-inpatient-hospital-settings-and-community-or-care-home-settings-for-adults-with-social-care-needs-pdf-1837336935877 [Accessed 06 July 2023].

NICE. (2020). Supporting adult carers. [online]. UK: National Institue for Health and Care Excellence (NICE). Available at: https://www.nice.org.uk/guidance/ng150/resources/supporting-adult-carers-pdf-66141833564869 [Accessed 06 July 2023].

Nielsen, L., Angus, J., Gastaldo, D., Howell, D. and Husain, A. (2013). Maintaining distance from a necessary intrusion: A postcolonial perspective on dying at home for Chinese immigrants in Toronto, Canada. *European Journal of Oncology Nursing,* 17(5): 649-656.

Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. and Van Den Bos, G. (1998). Cancer and caregiving: the impact on the caregiver's health. Psychooncology, 7(1): 3-13.

Noble, H. and Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-based nursing,* 18(2): 34-35.

Nolan, M., Grant, G. and Keady, J. (1996). *Understanding family care : a multidimensional model of caring and coping.* Buckingham : Open University Press.

Nolan, M. (2001). Working with family carers: towards a partnership approach. *Reviews in clinical gerontology,* 11(1): 91-97.

Nolan, M. (2003). Partnerships in family care. Maidenhead : Open University Press.

Nolan, M., Keady, J. and Grant, G. (1995). Developing a typology of family care: implications for nurses and other service providers. *Journal of Advanced Nursing,* 21(2): 256-265.

Nolan, M. and Grant, G. (1989). Addressing the needs of informal carers: a neglected area of nursing practice. *J Adv Nurs,* 14(11): 950-61.

Northouse, L., Katapodi, M., Song, L., Zhang, L. and Mood, D. (2010). Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA: a cancer journal for clinicians,* 60(5): 317-339.

Nyblom, S., Benkel, I., Carling, L., Löfdahl, E., Molander, U. and Öhlén, J. (2022). Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialised palliative home care: A qualitative study. *BMJ Open,* 12(5):e059577.

Okamoto, K. and Harasawa, Y. (2009). Emotional support from family members and subjective health in caregivers of the frail elderly at home in Japan. *Arch Gerontol Geriatr,* 49(1): 138-41.

Oliveira, D. (2017). The Development and Validation of the Dementia Quality of Life Scale for Older Family Carers (DQOL-OC). Doctoral thesis, University of Nottingham.

Olson, R. and Connor, J. (2015). When they don't die: Prognosis ambiguity, role conflict and emotion work in cancer caregiving. *Journal of Sociology,* 51(4): 857-871.

Oosterveld-Vlug, M., Custers, B., Hofstede, J., Donker, G., Rijken, P., Korevaar, J. and Francke, A. (2019). What are essential elements of

high-quality palliative care at home? An interview study among patients and relatives faced with advanced cancer. *BMC Palliat Care,* 18(1):96.

Opsomer, S., Pype, P., Lauwerier, E. and De Lepeleire, J. (2019). Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis. *PLoS One,* 14(8): e0221096.

Orb, A., Eisenhauer, L. and Wynaden, D. (2001). Ethics in qualitative research. *Journal of nursing scholarship,* 33(1): 93-96.

Palacio G,, Krikorian, A., Gomez-Romero, M. and Limonero, J. (2020). Resilience in caregivers: A systematic review. American Journal of Hospice & Palliative Medicine, 37(8): 648-658.

Patton, M. (2002). *Qualitative research & evaluation methods.* London : Sage.

Payne, S. and Hudson, P. (2008). *Family Carers in Palliative Care: A guide for health and social care professionals,* Oxford: Oxford University Press.

Pearlin, L., Mullan, J., Semple, S. and Skaff, M. (1990). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist,* 30(5): 583-594.

Penrod, J., Hupcey, J., Shipley, P., Loeb, S. and Baney, B. (2012). A model of caregiving through the end of life: seeking normal. *West J Nurs Res,* 34(2): 174-93.

Perpiñá-Galvañ, J., Orts-Beneito, N., Fernández-Alcántara, M., García-Sanjuán, S., García-Caro, M. and Cabañero-Martínez, M. (2019). Level of Burden and Health-Related Quality of Life in Caregivers of Palliative Care Patients. *Int J Environ Res Public Health,* 16(23),4806.

Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and society,* 35(1), 96-123.

Popay, J, Roberts, H , Sowden, A, Petticrew, M , Arai, L , Rodgers, M & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: Aproduct from ESRC Methods Programme.* Swindon, England: Institute for HealthResearch, Lancaster University.

Pope, N., Baldwin, P. and Lee, J. (2018). "I didn't expect to learn as much as I did": Rewards of caregiving in young adulthood. *Journal of Adult Development,* 25, 186-197.

Quill, T. and Abernethy, A. (2013). Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. *The New England journal of medicine,* 368(13), 1173-1175.

Qureshi, H and Walker A. (1986). Caring for elderly people the family and state. *In:* Phiuipson C and Walker A (ed.) *Ageing and Social Policy A Critical Assessment.*, Aldershot:Gower.

Radbruch, L. and Payne, S. (2009). *White paper on standards and* norms for hospice and palliative care in Europe: Part 1. European journal of palliative care. 16(6), 278-89

Reblin, M., Donaldson, G., Ellington, L., Mooney, K., Caserta, M. and Lund, D. (2016). Spouse cancer caregivers' burden and distress at entry to home hospice: The role of relationship quality. *Journal of Social and Personal Relationships,* 33(5), 666-686.

Reed, E. and Corner, J. (2015). Defining the illness trajectory of metastatic breast cancer. *BMJ Supportive & Palliative Care,* 5(4), 358-365.

Richards, S., Winder, R., Seamark, C., Seamark, D., Avery, S., Gilbert, J., Barwick, A. and Campbell, J. (2011). The experiences and needs of people seeking palliative health care out-of-hours: a qualitative study. *Primary Health Care Research & Development,* 12(2), 165-178.

Richman, J., Rosenfeld, L. and Hardy, C. (1993). The Social Support Survey: A validation study of a clinical measure of the social support process. *Research on Social Work Practice,* 3(3), 288-311.

Richmond, C., Ross, N. and Egeland, G. (2007). Social Support and Thriving Health: A New Approach to Understanding the Health of Indigenous Canadians. American journal of public health (1971), 97(10), 1827-1833.

Rieger, K. (2019). Discriminating among grounded theory approaches. *Nursing Inquiry,* 26(1), e12261.

Ritchie, J. and Lewis, J. (2003). *Qualitative research practice : a guide for social science students and researchers*, London : Sage Publications.

Robbins, M. (1998). *Evaluating Palliative Care: Establishing the Evidence Base*, Oxford University Press.

Robinson, C., Bottorff, J., Mcfee, E., Bissell, L., and Fyles, G. (2017). Caring at home until death: enabled determination. *Supportive Care in Cancer,* 25, 1229-1236.

Robinson, O. (2014). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology,* 11(1), 25-41.

Røen, I., Stifoss-Hanssen, H., Grande, G., Brenne, A.-T., Kaasa, S., Sand, K. and Knudsen, A. (2018). Resilience for family carers of advanced cancer patients—how can health care providers contribute? A qualitative interview study with carers. *Palliative medicine,* 32(8), 1410-1418.

Rogers, A., Karlsen, S. and Addington-Hall, J. (2000). 'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing,* 31(4), 768-774.

Rose, K. (1999). A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing,* 8(1), 81-88.

Rowland, C., Hanratty, B., Pilling, M., Van Den Berg, B. and Grande, G. (2017). The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliative Medicine,* 31(4), 346-355.

Royal collage of physicians. (2014). National Care of the Dying Audit of Hospitals. UK: Royal collage of physicians.

Ryan, G. and Sfar-Gandoura, H. (2018). Introduction to positivism, interpretivism and critical theory. *Nurse Res,* 25(4), 41-49.

Saldaña, J. (2013). *The coding manual for qualitative researchers.* London : SAGE.

Saldana, J., Leavy, P. and Beretvas, N. (2011). *Fundamentals of Qualitative Research.* Oxford University.

Sandgren, A., Axelsson, L., Bylund-Grenklo, T. and Benzein, E. (2021). Family members' expressions of dignity in palliative care: a qualitative study. Scandinavian journal of caring sciences, 35(3): 937-944.

Santerre-Theil, A., Brown, T., Körner, A. and Loiselle, C.(2022). Exploring healthcare professionals' experiences with informal family cancer caregiving. Supportive care in cancer, 30(9):7745-7754.

Santin, O., Mc Mullan, J., Jenkins, C., Anderson, L. and Mc Shane, C. (2022). Supporting someone with cancer during the COVID-19 pandemic: A mixed methods analysis of cancer carer's health, Quality of Life and need for support. *Health & social care in the community,* 30(5), e3246-e3252.

Schumacher, K. (1994). *Shifting patterns of self-care and caregiving during chemotherapy.* University of California, San Francisco.

Schumacher, K., Beidler, S., Beeber, A. and Gambino, P. (2006). A transactional model of cancer family caregiving skill. *Advances in nursing science,* 29(3), 271-286.

Seal, K., Murray, C. and Seddon, L. (2015). Family stories of end-of-life cancer care when unable to fulfill a loved one's wish to die at home. *Palliat Support Care,* 13(3), 473-83.

Seamark, D., Blake, S., Brearley, S., Milligan, C., Thomas, C., Turner, M., Wang, X. and Payne, S. (2014). Dying at home: a qualitative

study of family carers' views of support provided by GPs community staff. *Br J Gen Pract,* 64(629), e796-803.

Seers, K. (2015). Qualitative systematic reviews: their importance for our understanding of research relevant to pain. Br J Pain, 9(1):36-40.

Sekelja, N., Butow, P. and Tattersall, M. (2010). Bereaved cancer carers' experience of and preference for palliative care. *Support Care Cancer,* 18, 1219-28.

Selder, F. 1989. Life transition theory: the resolution of uncertainty. *Nurs Health Care,* 10(8), 437-40.

Seow, H., Barbera, L., Sutradhar, R., Howell, D., Dudgeon, D., Atzema, C., Liu, Y., Husain, A., Sussman, J. and Earle, C.(2011). Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. J Clin Oncol, 29(9):1151-8.

Sepúlveda, C., Marlin, A., Yoshida, T. and Ullrich, A. (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management,* 24(2), 91-96.

Shan, M., Swami, N., Pope, A., Rodin, G., Hannon, B., Nissim, R., Hales, S. and Zimmermann, C. (2018). “I didn't want to be in charge and yet I was”: Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psycho - Oncology,* 27(4), 1229-1236.

Shepperd, S., Gonçalves-Bradley, D., Straus, S. and Wee, B. (2021). Hospital at home: *home-based end-of-life care. Cochrane Database of Systematic Reviews,(7), CD009231-CD009231.*

Shiozaki, M., Morita, T., Hirai, K., Sakaguchi, Y., Tsuneto, S. and Shima, Y. (2005). Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. *Palliative Medicine,* 19(4), 319-327.

Shuy, R. (2001). In-person versus telephone interviewing *In:* Gubrium, J., and Holstein, J. (ed.) *Handbook of Interview Research.* SAGE Publications.

Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., Harrop, E., Noble, S., Sampson, C. and Nelson, A. (2019). Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper. *BMJ Supportive & Palliative Care,* 9(1), e14-e14.

Smith, B. and McGannon, K. (2018). Developing Rigor in Qualitative Research: Problems and Opportunities within Sport and Exercise Psychology. *International Review of Sport and Exercise Psychology,* 11(1),101-121.

Sobal, J. (2001). Sample Extensiveness in Qualitative Nutrition Education Research. *Journal of Nutrition Education,* 33(4), 184-192.

Son, M. and Chung, H. (2022). Chief complaints of patients with cancer who visit the emergency department over their oncologist's outpatient clinic in South Korea. BMC palliative care, 21(1):54-54.

Sparkes, A. and Smith, B. (2014). *Qualitative Research Methods in Sport, Exercise and Health: From Process to Product,* London: Routledge.

Spelten, E., Timmis, J., Heald, S. and Duijts, S. 2019. Rural palliative care to support dying at home can be realised; experiences of family members and nurses with a new model of care. *Australian Journal of Rural Health,* 27(4), 336-343.

Spencer, L., Ritchie, J., Lewis, J. and Dillon, L. (2004). Quality in qualitative evaluation: a framework for assessing research evidence[online]. Available at: https://www.cebma.org/wp-content/uploads/Spencer-Quality-in-qualitative-evaluation.pdf
[Accessed 06 July 2023]

Stajduhar, K. and Davies, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliat Med,* 19(1), 21-32.

Stajduhar, K., Funk, L., Toye, C., Grande, G., Aoun, S. and Todd, C. (2010). Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine,* 24(6), 573-593.

Stajduhar, K., Martin, W., Barwich, D. and Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing,* 31(1), 77-85.

Stall, N., Campbell, A., Reddy, M. and Rochon, P. (2019). Words Matter: The Language of Family Caregiving. *Journal of the American Geriatrics Society (JAGS),* 67(10), 2008-2010.

Standing medical advisory committee and standing nurse and midwifery advisory committee.(1992). Principles and Provision of

Palliative Care. London: Standing medical advisory committee and standing nurse and midwifery advisory committee.

Stark, L., Tofthagen, C., Visovsky, C. and McMillan, S. (2012). The Symptom Experience of Patients with Cancer. *J Hosp Palliat Nurs,* 14(1), 61-70.

Starks, H. and Brown Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative health research,* 17(10), 1372-1380.

Steindal, S., Nes, A., Godskesen, T., Dihle, A., Lind, S., Winger, A. and Klarare, A. (2020). Patients' Experiences of Telehealth in Palliative Home Care: Scoping Review. *Journal of medical Internet research,* 22(5), e16218-e16218.

Stern, A., Valaitis, R., Weir, R. and Jadad, A. (2012). Use of home telehealth in palliative cancer care: A case study. *Journal of Telemedicine and Telecare,* 18(5), 297-300.

Stiel, S., Heckel, M., Bussmann, S., Weber, M. and Ostgathe, C. (2015). End-of-life care research with bereaved informal caregivers – analysis of recruitment strategy and participation rate from a multi-centre validation study. *BMC Palliative Care,* 14(1), 21.

Strang, V. and Koop, P. (2003). Factors which influence coping: Home-based family caregiving of persons with advanced cancer. *Journal of Palliative Care,* 19(2), 107-114.

Strauss, A. (1984). *Chronic illness and the quality of life.* St. Louis: Mosby.

Strauss, A. and corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park,CA: Sage.

Strauss, A. & Corbin, J. (1998). *Basics of qualitative research : techniques and procedures for developing grounded theory.* London : SAGE.

Sutton, J. and Austin, Z. (2015). Qualitative research: data collection, analysis, and management. *The Canadian journal of hospital pharmacy,* 68(3), 226.

Tarberg, A., Kvangarsnes, M., Hole, T., Thronæs, M., Madssen, T. and Landstad, B. (2019). Silent voices: Family caregivers' narratives of involvement in palliative care. Nursing open, 6(4): 1446-1454.

Taylor, J. and Pagliari, C. (2018). #Deathbedlive: the end-of-life trajectory, reflected in a cancer patient's tweets. BMC Palliative Care, 17(1):17.

Teno, J., Weitzen, S., Fennell, M. and Mor, V. (2001). Dying trajectory in the last year of life: does cancer trajectory fit other diseases? Journal of Palliative Medicine, 4(4), 457-464.

Thanh, N. and Thanh, T. (2015). The interconnection between interpretivist paradigm and qualitative methods in education. *American Journal of Educational Science,* 1(2), 24-27.

The social research association. (2012). A Code of Practice for the Safety of Social Researchers. UK: The social research association, .

The University of Nottingham. (2012). Health and Safety Arrangements for Lone Working. Nottingham, UK: The University of Nottingham

The University of Nottingham. (2018a). Data Protection Policy. Nottingham.UK: The University of Nottingham.

The University of Nottingham.(2018b). Data retention policy Nottinggham.UK: The University of Nottingham

Thomas, C., Morris, S. and Clark, D. (2004). Place of death: preferences among cancer patients and their carers. *Soc Sci Med,* 58(12), 2431-44.

Thomas, J. and Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology,* 8(1), 1-10.

Thomas, P. (2010). *Toward developing a web-based blended learning environment at the university of botswana.* Doctoral thesis, University of South Africa.

Thomson, S. (2011). Sample Size and Grounded Theory;Grounded Theory-Sample Size. Journal of Administration and Governance, 5(1), pp.45-52.

Tolbert, E., Bowie, J., Snyder, C., Bantug, E. and Smith, K. (2018). A qualitative exploration of the experiences, needs, and roles of caregivers during and after cancer treatment: "That's what I say. I'm a relative survivor". Journal of Cancer Survivorship, 12(1):134-144.

Tong, A., Sainsbury, P. and Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19(6), 349-357.

Topf, L., Robinson, C. and Bottorff, J. (2013). When a desired home death does not occur: The consequences of broken promises. *Journal of Palliative Medicine,* 16(8), 875-880.

Totman, J., Pistrang, N., Smith, S., Hennessey, S. and Martin, J. (2015). 'You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliative Medicine,* 29(6), 496-507.

Tsaras, K., Papathanasiou, I., Mitsi, D., Veneti, A., Kelesi, M., Zyga, S. and Fradelos, E. (2018). Assessment of Depression and Anxiety in Breast Cancer Patients: Prevalence and Associated Factors. Asian Pac J Cancer Prev, 19(6):1661-1669.

Twigg, J. and *Atkin, K.* (1994). *Carers perceived : policy and practice in informal care.* Buckingham : Open University Press.

Twycross, R. (2021). *Introducing palliative care*, London : Pharmaceutical Press.

Uceda-Torres, M., Rodríguez-Rodríguez, J., Alvarado-Gómez, F., Sánchez-Ramos, J. and Mcgrath, P. (2016). Informal Caregivers of Palliative Oncohematologic Patients: The Invisible Guests: An Exhaustive Review of the Literature Available. *American Journal of Hospice and Palliative Medicine*, 33(7),691–702.

UK Government. (2016). Guidance Care Act factsheets. UK Government[Online].Available at https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets [Accessed 06 July 2023].

Vermorgen, M., Vandenbogaerde, I., Van Audenhove, C., Hudson, P., Deliens, L., Cohen, J. and De Vleminck, A.(2021). Are family carers part of the care team providing end-of-life care? A qualitative interview study on the collaboration between family and professional carers. Palliative medicine, 35(1):109-119.

VIerhout, M., Varenbut, J., Amos, E., Buchman, S., Husain, A., Meuser, J. and Bernstein, M. (2019). Loss of relationship: a qualitative study of families and healthcare providers after patient death and home-based palliative care ends. Annals of palliative medicine, 8(2):130-139.

Wahid, A., Sayma, M., Jamshaid, S., Kerwat, D., Oyewole, F., Saleh, D., Ahmed, A., Cox, B., Perry, C. and Payne, S. (2018). Barriers and facilitators influencing death at home: A meta-ethnography. *Palliative Medicine,* 32(2), 314-328.

Wan, A., Lung, E., Ankita, A., Li, Z., Barrie, C., Baxter, S., Benedet, L., Mirhosseini, M., Mirza, R., Thorpe, K., Vadeboncoeur, C. and Klinger, C. (2022). Support for Informal Caregivers in Canada: A Scoping Review from a Hospice and Palliative/End-of-Life Care Lens. Journal of palliative care, 37(3): 410-418.

Wang, T., Molassiotis, A., Chung, B. P. M., Zheng, S.-L., Huang, H.-Q. and Tan, J.-Y. (2021). A qualitative exploration of the unmet information needs of Chinese advanced cancer patients and their informal caregivers. BMC palliative care, 20(1):1-83.

Ward-Griffin, C., Mcwilliam, C. and Oudshoorn, A. (2012). Relational Experiences of Family Caregivers Providing Home-Based End-of-Life Care. *Journal of Family Nursing,* 18(4), 491-516.

Watling, C. and Lingard, L. (2012). Grounded theory in medical education research: AMEE Guide No. 70. *Medical teacher,* 34(10), 850-861.

Wennman-Larsen, A. and Tishelman, C. (2002). Advanced home care for cancer patients at the end of life: A qualitative study of hopes and expectations of family caregivers. *Special Issue: The challenging complexity of cancer care research.,* 16(3), 240-247.

Wennman, I., Ringheim, A. and Wijk, H. (2020). "We Are Here for You All the Way"—Patients' and Relatives' Experiences of Receiving Advanced Home Care. American journal of hospice & palliative medicine, 37(9):669-674.

Wilcock, J., Froggatt, K. and Goodman, C.(2008). End of life care In: Downs, M. and Bowers, B. (eds.) Excellence in dementia care : Research into practice, Maidenhead: McGraw Hill; Open University Press.

Wilkinson, A. and Lynn, J. (2005). Caregiving for advanced chronic illness patients. *Techniques in regional anesthesia & pain management,* 9(3), 122-132.

Williams, A., Crooks, V., Stajduhar, K., Allan, D. and Cohen, S. (2006). Canada's Compassionate Care Benefit: Views of family caregivers in chronic illness. *International journal of palliative Nursing,* 12(9), 438-445.

Willig, C. (2008). Introducing qualitative research in psychology: adventures in theory and method, 2nd ed. Maidenhead: McGraw Hill; Open University Press.

Wimpenny, P. and Gass, J. (2000). Interviewing in phenomenology and grounded theory: is there a difference? *J Adv Nurs,* 31(6), 1485-92.

World Health Organisation. (2019). *WHO Definition of Palliative Care* [Online]. World Health Organisation. Available at : https://www.who.int/cancer/palliative/definition/en/ [Accessed June 2019].

World Health Organisation. (2022). *Cancer Fact Sheet* [Online]. World Health Organisation. Available at : https://www.who.int/news-room/fact-sheets/detail/cancer [Accessed on 16-11-2022 2022].

Xie, H., Cheng, C., Tao, Y., Zhang, J., Robert, D., Jia, J. and Su, Y. (2016). Quality of life in Chinese family caregivers for elderly people with chronic diseases. *Health and Quality of Life Outcomes,* 14(1),99-99.

Yang, W., Lee, R., Kuparasundram, S., Tan, T., Chan, Y., Griva, K. and Mahendran, R.(2021). Cancer caregivers unmet needs and emotional states across cancer treatment phases. PLoS One,16(8):e0255901.

Yildiz, B., Korfage, I., Witkamp, E., Goossensen, A., Van Lent, L., Pasman, H., Onwuteaka-Philipsen, B., Zee, M. and Van Der Heide, A. (2022). Dying in times of COVID-19: Experiences in different care settings - An online questionnaire study among bereaved relatives (the CO-LIVE study). *Palliat Med,* 36(4), 751-761.

Yilmaz, K. (2013). Comparison of Quantitative and Qualitative Research Traditions: epistemological, theoretical, and methodological differences. *European journal of education,* 48(2), 311-325.

Yu, M., Guerriere, D. and Coyte, P. (2015). Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health & Social Care in the Community,* 23(6), 605-618.

Yuan, Q., Wang, P., Tan, T., Devi, F., Poremski, D., Magadi, H., Goveas, R., Ng, L., Chong, S. and Subramaniam, M. (2021). Coping Patterns Among Primary Informal Dementia Caregivers in Singapore and Its Impact on Caregivers-Implications of a Latent Class Analysis. *Gerontologist,* 61(5), 680-692.

Zarit, S., Reever, K. and Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *The Gerontologist,* 20(6), 649-655.

Zavagli, V., Raccichini, M., Ercolani, G., Franchini, L., Varani, S. and Pannuti, R. (2019). Care for Carers: an Investigation on Family Caregivers' Needs, Tasks, and Experiences. Transl Med UniSa, 19: 54-59.

APPENDICES

Appendix 1. Search strategy

Carer* OR Caregiv*OR “family (care*) Caregiv*” OR “spousal (Care*) Caregiv*” OR “Informal (care*)” caregiv* OR Unpaid (care*) Caregiv* OR relatives* OR next of kin*OR family member*AND “Palliative care*” OR “Hospice care*” OR “Terminal Care*” OR “end of life care*” OR supportive (service*) care*AND Home* OR Communit* OR Community nurs* OR district nurs* OR GP* OR Outreach*AND “People with cancer*” OR “cancer patient*” OR “cancer survivor*” OR cance

Appendix 2. Critical appraisal of studies using CASP tool

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score/10
Andershed and Ternestedt , 1998	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	9
Aranda and Peerson, 2001	C	Y	C	Y	Y	C	Y	Y	Y	Y	7
Arber et al,2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Brazil et al, 2010	Y	Y	C	C	Y	C	Y	Y	Y	C	6
BrobÄCk and BerterÖ, 2003	Y	Y	Y	Y	Y	C	Y	Y	Y	C	8
Chapple et al., 2011	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8
Duggleby et al., 2011	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Dumont et al., 2008	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8
Epiphaniou et al., 2012	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8
Exley and Tyrer, 2005	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	9
Grbich et al., 2001	Y	Y	C	Y	Y	C	C	Y	Y	Y	7
Harding et al., 2012	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Holmberg, 2006b	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Holmberg, 2006a	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Hudson, 2004	Y	Y	C	C	Y	N	Y	C	C	Y	5
Johnston et al., 2012	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Klarare et al., 2017	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Lee et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Linderholm and Friedrichsen, 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Lovatt et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Luijkx and Schols, 2009	Y	Y	C	Y	Y	N	C	C	Y	Y	6
Maddalena et al., 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score/10
McCaughan et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9
Milberg and Strang, 2004	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Miranda do Vale et al., 2019	Y	Y	C	Y	Y	N	Y	Y	Y	Y	8
Mok et al., 2003	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9
Nielsen et al., 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Oosterveld-Vlug et al., 2019	Y	Y	N	Y	Y	N	Y	Y	Y	Y	8
Opsomer et al., 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Richards et al., 2011	Y	Y	C	Y	Y	N	Y	Y	Y	Y	8
Robinson et al., 2017	Y	Y	Y	Y	Y	C	Y	C	Y	Y	8
Røen et al., 2018	Y	Y	C	Y	Y	N	Y	Y	Y	Y	8
Rose, 1999	Y	Y	Y	Y	Y	N	Y	C	Y	Y	8
Seal et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Sekelja et al., 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Shan et al., 2018	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Spelten et al., 2019	Y	Y	C	Y	Y	Y	Y	C	Y	Y	8
Stajduhar et al., 2008	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Strang and Koop, 2003	Y	Y	C	Y	C	C	Y	Y	Y	Y	7
Totman et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
Ward-Griffin et al., 2012	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9
Wennman-Larsen and Tishelman, 2002	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	9
N.B: Y=Yes N= No C= Can't tell											

Appendix 3. Participation documents

Appendix 3.1. Study invitation letter



Letter of Invitation for a Research study

Dear Sir/Madam,

I am a PhD student at the Faculty of Medicine and Health Sciences at the University of Nottingham. I have a nursing background and I am very interested in family caring research and the assistance given to enable family carers to support their relatives with cancer. Therefore, I would like to invite you to consider participating in a research study titled “Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care”.

The study aims to explore the experiences of family carers of people with cancer who are receiving or received home-based palliative care. I am looking for active and former carers who support a relative with cancer at home, you have been contacted by the care team and received this invitation because you are thought fit these criteria.
The study will involve a single interview which will be conducted remotely either online or by telephone) where you would be asked about your experiences of support received during your caring for a relative with cancer. The information we will get from this study may help in reshaping the supportive services provided to family carers in the future, so your participation is valued, and your views are important.
If you are interested in finding out more, please, contact me at (study phone number) or via email (University email) to arrange a convenient time to discuss you to discuss the study with you. Please note, this will not commit you to participation in the study.
Thank you for your time to read this invitation.

Yours sincerely,

Ahmed Sharaf
PhD Research Student
School of Health Sciences
University of Nottingham
Room B316, B floor, Medical School
Queen’s Medical Centre, Nottingham, NG7 2HA

Appendix 3.2. Participant Information Sheet



Participant Information Sheet
(Final version 3.1: 16-07-2020)
IRAS Project ID: 273078

Title of Study: **Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care**
Name of Chief Investigator:
Local Researcher(s):
We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

People with cancer are considered to be a major group who receive palliative care at home. In light of the challenges faced by many family carers in managing their situation, an effective support system should be present to enable them to deliver optimum care to the person with cancer while at the same time, preserving their physical and psychological well-being. The current research literature indicates that not enough is known on how family carers experience such support. Therefore, the aim of the study is to explore the experiences of family carers of people with cancer who are receiving or received home-based palliative care.

Why have I been invited?

You are being invited to take part because you either an active or have been a family carer of a person with cancer who receives or received palliative care at home. We are inviting fifty family carers participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Your involvement in the study will be in the form of an interview. You will be interviewed at a place of convenience to you (e.g. your home, at the university etc.) and at the time of your choice, interviews will be conducted remotely either online or by telephone.The interview will last approximately 30-60 minutes and be audio recorded with your permission, however, in case of video calls it will be video recorded (participants will be given the option of switching off their camera if they do not wish to be video recorded). The interview will be about your experiences of providing support to a person with cancer while receiving palliative care at home. You will be invited to receive a summary of the findings of this study once it has been completed.

Expenses and payments

Travel expenses will be offered for any visits incurred as a result of participation if the interview venue is not your home or the visit was not a usual care visit.

What are the possible disadvantages and risks of taking part?

Some people might find talking about their experiences to be upsetting. The researcher who will interview you will be aware of this and will be able to discuss access to further support should you need it.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help in reshaping the supportive services provided to family carers in the future. Additionally, it is evident from similar research studies that participants might feel they benefit from sharing their thoughts and ideas.

What happens when the research study stops?

This study will involve participation in one interview only. After that we will be happy to share a summary of the findings with you, if you provide your postal and/or email address for this purpose. These personal details will be kept confidential and will be destroyed after this.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The chief investigator's contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting:
Joanne Lymn,
Head of school of Health Sciences,
Room B234, B Floor, Medical School,
Queens Medical Centre,
Nottingham,
NG7 2UH
Tel.0115 8230805
joanne.lymn@nottingham.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.
Each recorded interview will be transcribed by the co- investigator or by a professional transcriber with whom a confidentiality agreement will be in place.
Where possible information about you which leaves the [site] will have your name and address removed and a unique code will be used so that you cannot be recognised from it.

Your contact information will be kept by the University of Nottingham for one year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

The results of this study will be used in a thesis for an educational qualification (PhD) for one of the research team which is due to finish by September2021. The thesis will be published online on the University of Nottingham thesis and dissertation online library; findings will be published in academic journals and discussed in scientific conferences which may contain direct quotes from your interview after anonymising them so you will not be identified. Your personal details will not appear in any publication.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The Newton Mosharafa Research Fund as a Ph.D. scholarship.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Oxford C Research Ethics Committee.

Further information and contact details.

If you have any queries, please contact:

Chief investigator **DR. Philip Clissett,**
Room B 225, B floor
School of Health Sciences,
University of Nottingham,
Queens Medical Centre, Nottingham, NG7 2HA
Phone: 0115 823 0954
Email: University email.

Co-investigator **Ahmed Sharaf,**
B336 Postgraduate Research Office, B floor
School of Health sciences
University of Nottingham
Queen's Medical Centre, Nottingham, NG7 2HA
Phone: Study phone number.
Email: University email.

Appendix 3.3. Consent form

University of Nottingham
UK | CHINA | MALAYSIA

CONSENT FORM

(Final version 3.0: 16/07/2020)

Title of Study: Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care

IRAS Project ID: 273078

Name of Researcher:

Name of Participant:

	Please initial box
1. I confirm that I have read and understand the information sheet version number 3.1 dated 16-07-2020 for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.	☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.	☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.	☐
5. I am aware that I have the option to turn the camera off if I do not want the interview to be video recorded and that only the audio of the interview will be recorded.	☐
6. I understand that the information collected about me will be used to support. other research in the future and may be shared anonymously with other researchers.	☐
7. I agree to take part in the above study.	☐
8. I would like to be contacted again to receive the summary of findings (you can take part in the study without agreeing to this).	☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Additional part if the patient was present during the interview.

I understand that any comments that I will make during the interview will be audio recorded.	☐

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 3.4. Interview guide



University of Nottingham
UK | CHINA | MALAYSIA

Interview guide

Title of Study: Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care

IRAS Project ID: 273078

The information below gives an outline of the topics that will be discussed within the interview. The order may change, depending on the issues that the participant raises without prompting.

Greeting and ice breaking:

Introduction and review of participant information sheet and signing informed consent.

(Many thanks for accepting participation in this study and talking about your experiences with palliative care services. I really appreciate that)

Checking socio-demographic data such age, education, occupation etc.

Introductory questions:

1. Could you tell me a bit about yourself and your husband/wife/partner/mother……?
2. How do you feel about your caregiving experiences and your husband/wife/partner/mother……?

General topics areas guiding questions.

3. Could you tell me how the decision was made to start having support services for your husband/wife/partner/mother……?
4. Could you tell me about types of support services you received?
5. What were your expectations for support services?
6. How was the access or selection of support services explained and made available for you?

7. Could you tell more about your experiences about the services you mentioned earlier?
8. Were you aware of any other support options that might have been available to you?

Focused topic areas:

9. What kind of support was most useful for you?
10. What kind of support was unhelpful to you?
11. How many care team members come to support you at home and how often?
12. Could you talk about the moments you felt you were well supported by the care team?
13. Were there any occasions when you felt that you needed more support from the care, could you tell about this?
14. Could you tell me about challenges you have experienced while caring for your husband/wife/partner/mother…….and to what extent were the care team supportive to you?
15. In your opinion how might the support provided to you be improved?
16. Do you want to talk about anything else?

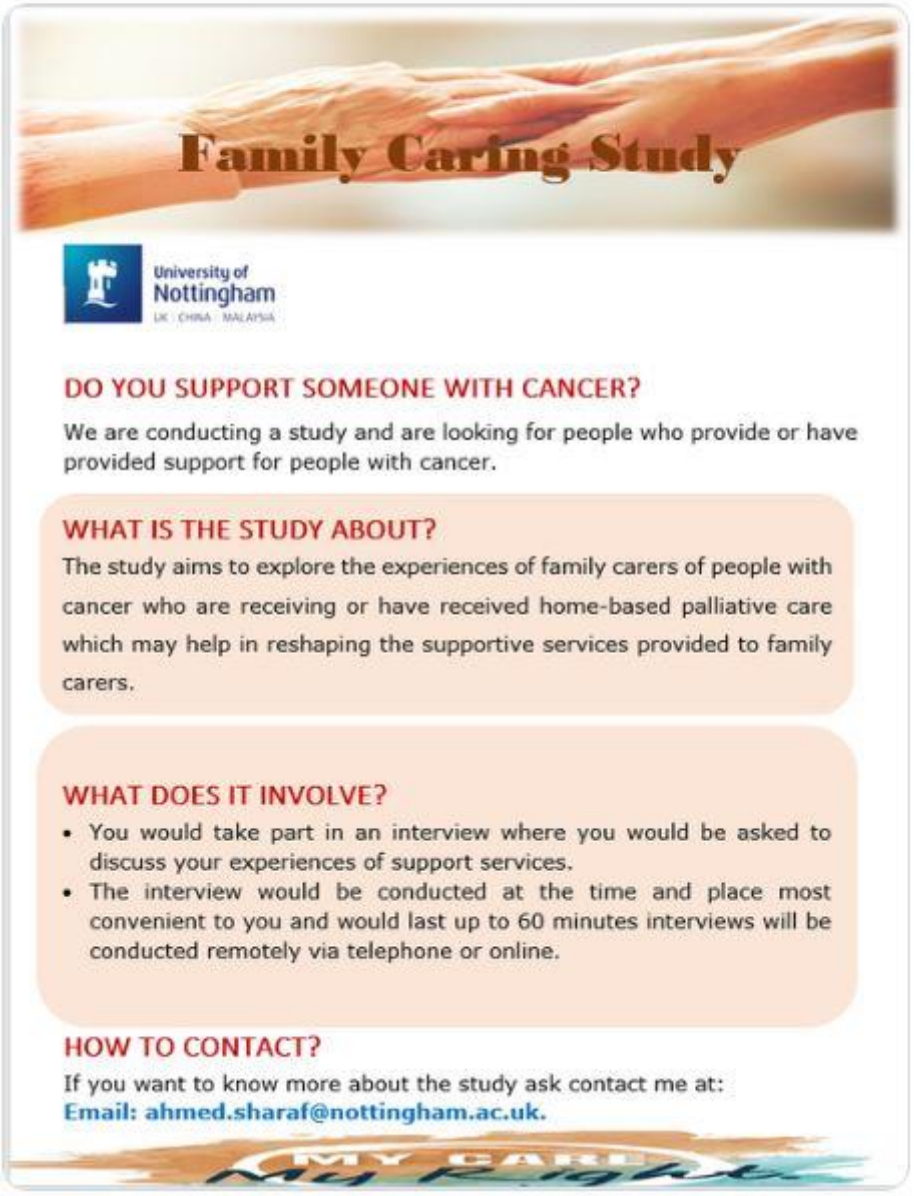
Probes: Could you tell me more about that, could you give more details about this? And what happen after that? How did you feel about that? You have mentioned earlier about…. Can we talk more about that?

Checking: So, I can summarise what you have told me about …… in ……. /would it be right to say ……..

Closing and summary of what have been said and thanking participants for their time.

Appendix 3.5. Study poster and social media advertising

Are you #caring/have cared for someone with #cancer at home and received support services? @UoNFacultyMHS scholar conducting a study to explore your valued experiences? @CarersUK @CarersTrust @CarersFedNews If interested contact me at: ahmed.sharaf@nottingham.ac.uk



We are conducting a study and are looking for people who provide or have provided support for people with cancer. The study aims to explore the experiences of family carers of people with cancer who are receiving or who have received home-based palliative care. If you would like any more information, please contact the hospice and ask for Research Nurses. They will be in work each Wednesday 10-12AM.



University of Nottingham
UK | CHINA | MALAYSIA

DO YOU SUPPORT SOMEONE WITH CANCER?

We are conducting a study and are looking for people who provide or have provided support for people with cancer.

WHAT IS THE STUDY ABOUT?

The study aims to explore the experiences of family carers of people with cancer who are receiving or have received home-based palliative care which may help in reshaping the supportive services provided to family carers.

WHAT DOES IT INVOLVE?

- You would take part in an interview where you would be asked to discuss your experiences of support services.
- The interview would be conducted at the time and place most convenient to you and would last up to 60 minutes interviews will be conducted remotely via telephone or online.
- Expenses will be offered.

HOW TO CONTACT?

If you want to know more about the study ask [Your hospice team / care team] about the studies documents OR contact me at:

Email: ahmed.sharaf@nottingham.ac.uk. **M:**



Experiences of Receiving Home Based - Palliative Care (Final version 2.1: 16/07/2020)

Appendix 3.6. List of support services



Counselling and Support Services

Service/Agency	Website	Contact
Let's Talk-Wellbeing	http://www.nottinghamshirehealthcare.nhs.uk/letstalkwellbeing	Phone: 0115 969 1300
Cruse bereavement care	nottinghamshirecruse.org.uk	Phone: 0115 9244404 Email: nottinghamshire@cruse.org.uk
Carers federation counselling services	https://www.carersfederation.co.uk/services/counselling/	Phone: 0115 962 9310 Email: info@carersfederation.co.uk
Samaritans	https://www.samaritans.org/	Phone: 116 123 Email: jo@samaritans.org
Trent PTS (Psychological Therapy Services)	https://www.trentpts.co.uk/	Phone Nottingham: 0115 896 3160 Derbyshire: 01332 265659 Chesterfield: 01246 387 498 Email: enquiries@trentpts.co.uk
Insight Healthcare	https://www.insighthealthcare.org/	
Turning Point Talking Therapies	http://www.turning-point.co.uk/	

***Ask your GP for the best option for you or you can make a self-referral by contacting these services.**

Appendix 4. Ethics and regulatory approvals

Appendix 4.1. Primary ethics approval

NHS
Health Research Authority

South Central - Oxford C Research Ethics Committee
Level 3, Block B
Whitefriars Building
Lewins Mead
Bristol
BS1 2NT

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

14 February 2020

Dr Philip Clissett
QMC, University of Nottingham
Nottingham University
NG7 2RD

Dear Dr Clissett

Study title:	**Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care**
REC reference:	**20/SC/0029**
Protocol number:	**19092**
IRAS project ID:	**273078**

The Research Ethics Committee reviewed the above application at the meeting held on 31 January 2020. Thank you for attending with Mr Ahmed Sharaf to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Number	Condition
1	Update the protocol to reflect the following:

	a. State that the participant will be approached within 2 years of their bereavement. b. Include the comparison between active and bereaved carers.
2	**Consent form:** Include a point for the patient to agree to the recording of the interview.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS/HSC sites taking part in the study taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study poster - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Covering letter on headed paper [Study initiation letter - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors		30 July 2019

only) [Sponsor Insurance]		
Interview schedules or topic guides for participants [Interview guide-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
IRAS Application Form [IRAS_Form_18122019]		18 December 2019
Letter from sponsor [Sponsor Letter]	1	18 December 2019
Letters of invitation to participant [Invitation letter-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Other [Delegation log-Experiences of Receiving Home Based - Palliative Care]	1	09 December 2019
Other [Distress protocols-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Other [List of counseling services- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Other [Univeristy of Nottingham lone-working Policy - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]		17 July 2012
Other [Social Research Association(SRA)_ safety_code_of_practice-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Participant consent form [Consent form-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Participant information sheet (PIS) [PIS- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Referee's report or other scientific critique report [Confirmation of PhD transfer form- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]		25 November 2019
Research protocol or project proposal [Study Protocol-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for Chief Investigator (CI) [CV-Philip-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for student [CV-Ahmed-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for supervisor (student research) [CV-Philip-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for supervisor (student research) [CV-Katharine-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

20/SC/0029	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp
Dr Lee Potiphar
Chair

E-mail: nrescommittee.southcentral-oxfordc@nhs.net

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers" [SL-AR2 for other studies]
Copy to:	Ms Angela Shone

Appendix 4.2. Ethics amendment approval

NHS
Health Research Authority

South Central - Oxford C Research Ethics Committee
Level 3, Block B
Whitefriars Building
Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8379

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

24 July 2020

Mr Ahmed Sharaf
PhD student
N/A
Room B 316 , B floor, School of Health Sciences
Queens Medical Centre
Nottingham University
NG7 2RD

Dear Mr Sharaf

Study title:	**Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care**
REC reference:	**20/SC/0029**
Protocol number:	**19092**
Amendment number:	**SA.01**
Amendment date:	**25 June 2020**
IRAS project ID:	**273078**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment tool]	SA.01	25 June 2020
Copies of advertisement materials for research participants [Webpage link]	1.0	25 June 2020
Copies of advertisement materials for research participants [Study Poster - Experiences of Receiving Home Based-Palliative care Final Version 2.1-16-07-2020.]	2.1	16 July 2020
Letters of invitation to participant [Invitation Letter -Experiences of Receiving Home Based-Palliative care Final Version 2.1.date 16-07-2020.]	2.1	16 July 2020
Participant consent form [Consent form-Experiences of Receiving Home Based - Palliative Care - Final Version 3.0 date 16-07-2020]	3.0	16 July 2020
Participant information sheet (PIS) [PIS- Experiences of Receiving Home Based - Palliative Care - Final Version3.1 date 16-07-2020]	3.1	16 July 2020
Research protocol or project proposal [Study Protocol -Experiences of receiving Home Based-Palliative Care - Final Version 3.1 16-07-2020.]	3.1	16 July 2020

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 273078:	Please quote this number on all correspondence

Yours sincerely



Dr Lee Potiphar
Chair

E-mail: oxfordc.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Appendix 4.3. HRA approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Philip Clissett
QMC, University of Nottingham
Nottingham University
NG7 2RD

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

18 March 2020

Dear Dr Clissett

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care
IRAS project ID:	273078
Protocol number:	19092
REC reference:	20/SC/0029
Sponsor	University of Nottingham

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 273078. Please quote this on all correspondence.

Yours sincerely,

Maeve Ip Groot Bluemink
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Ms Angela Shone

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants [Study poster - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Covering letter on headed paper [Study initiation letter - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]		30 July 2019
Interview schedules or topic guides for participants [Interview guide-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	2	25 February 2020
IRAS Application Form [IRAS_Form_18122019]		18 December 2019
Letter from sponsor [Sponsor Letter]	1	18 December 2019
Letters of invitation to participant [Invitation letter-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Organisation Information Document [Site Type 1]	2.0	21 January 2020
Organisation Information Document [Site Type 2]	2.0	21 January 2020
Other [Transcriber Non-Disclosure Agreement -Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-02-2020]	1	25 February 2020
Other [Response to Ethics Review and HRA assessment Queries-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-02-2020]	1	25 February 2020
Other [Delegation log-Experiences of Receiving Home Based - Palliative Care]	1	09 December 2019
Other [Distress protocols-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Other [List of counseling services- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Other [Univeristy of Nottingham lone-working Policy - Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]		17 July 2012
Other [Social Research Association(SRA)_ safety_code_of_practice-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Participant consent form [Consent form-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	2	25 February 2020
Participant information sheet (PIS) [PIS- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	2	25 February 2020
Referee's report or other scientific critique report [Confirmation of PhD transfer form- Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]		25 November 2019
Research protocol or project proposal [Study Protocol-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	2	25 February 2020
Schedule of Events or SoECAT [Site Type 1]	1 (assessed)	17 February 2020
Schedule of Events or SoECAT [Site Type 2]	1 (assessed)	17 February 2020
Summary CV for Chief Investigator (CI) [CV-Philip-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019

Summary CV for student [CV-Ahmed-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for supervisor (student research) [CV-Katharine-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019
Summary CV for supervisor (student research) [CV-Philip-Experiences of Receiving Home Based - Palliative Care - Final Version 1.0 date 25-11-2019]	1	25 November 2019

Appendix 5. Transcriber Non-Disclosure Agreement

University of Nottingham
UK | CHINA | MALAYSIA

Transcriber Non-Disclosure Agreement

Project Title:	Qualitative Study of Experiences of Family Carers of People with Cancer Receiving Home Based – Palliative Care
Chief investigator:	Dr. Philip Clissett
Researcher:	Ahmed Sharaf
Institution:	School of Health Sciences (SHS), University of Nottingham (UoN).
Purpose of research:	To explore FCs' experiences and perspectives about formal support services received while caring for PwC at home during the last year of life.
Transcriber:	
Transcriber's organisation:	

As a transcriber of this research, I, _____, understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this non-disclosure agreement.

I, _____, agree not to share any information on these recordings with anyone except the Researcher of this project. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I, _____, agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) with anyone other than the Researcher.

2. Take reasonable technical and non-technical measures to keep all research information in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) secure while it is in my possession.

3. Take reasonable technical and non-technical measures to maintain the security of any storage device (e.g. laptop and desktop PC, Mac, USB stick, etc.) that host the said research information.

4. Not keep the research information in any third party cloud storage service, unless the files are in encrypted format and this is agreed by the researcher.

5. Return all research information in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) to the Researcher, in a secure method, when I have completed the transcription tasks.

Adopted from: London School of Economics and Political Science (LSE). Transcriber Non-Disclosure Agreement. London School of Economics and Political Science, UK, 2016.Available at; https://info.lse.ac.uk/staff/divisions/dts/assets/documents/policies/SampleNDA-Final.pdf

6. After consulting with the Researcher, securely erase or destroy all research information in any form or format regarding this research project that is not returnable to the researcher (e.g. information stored on my computer hard drive).

7. Inform UoN if we are aware of, or suspect there might be, a data breach while the data are within our own, or our subcontractor's storage systems. (This is particularly an obligation under the upcoming General Data Protection Regulation.)

Transcriber :

_____	_____	_____
(Print name)	**(signature)**	**(Date)**

Researcher:

_____	_____	_____
(Print name)	**(signature)**	**(Date)**

Adopted from: London School of Economics and Political Science (LSE). Transcriber Non-Disclosure Agreement. London School of Economics and Political Science, UK, 2016.Available at; https://info.lse.ac.uk/staff/divisions/dts/assets/documents/policies/SampleNDA-Final.pdf

Appendix 6. Risk assessment

University of Nottingham
UK | CHINA | MALAYSIA

Activity / Task Risk Assessment Form

Business Unit: School of Health Sciences	**Location(s) of Activity:** Research sites in the community (Outside university)	**Risk Assessment Ref:**
Activity Title: Experiences of family carers of people with cancer receiving home-based end-of-life care services "Research interviews"		
Activity Outline: This is a qualitative interview study that involves conducting single face-to-face interview with active / former family carers with people with cancer receiving or received palliative care at home about their experiences of support. The interview will be conducted at the time and the place convenient to participants.		
Those at risk / affected parties: • Student researcher • Research participants		
Risk Assessor Name: **Ahmed Sharaf**	Signature:	Date:
Responsible person / Line Manager Name:	Signature:	Date:
Master Risk Assessment Reference where applicable: N/A	**Related procedure references or links:**	
Review Period:		

What are the hazards?	List the harm associated with the hazard	Risk Evaluation without controls in place High/Med/Low	What control measures are, or will be put, in place to control the risk? List all elimination, substitution, engineering and/or administrative controls	Risk Evaluation with controls in place High/Med/Low
Conducting interviews at participants' home / Lone working	Physical assault/ abuse	Low	• Recruitment of study participants will be through gatekeepers who have the knowledge about the potential participants and would advise about safety issues. • The site of interview will not be exclusively at home as it will be determined by the participants, telephone and internet interviews will be considered. • Researcher will keep mobile phone charged and available for making calls. • Interviews during the dark hours will be discouraged. • Checking the public transportation link to the site will be done and if no suitable transportation available, arrangements will be done for a private taxi for a lift. • A pre-interview phone call will be done to check the home circumstances as possible.	Low

			• If something makes the research felt uneasiness, an excuse will be displayed and interview will be ended. • Arrangement will be made with supervisors to know the place and time of interviews and any concerns prior to interview will be disclosed.	
Conducting interviews at participants' home / Lone working	Risk of being in a comprising situation, in which there might be accusations of improper behaviour	Low	• It is a requirement for having a research passport for this kind of • Researcher will be trained not to be alone with a child / young/ vulnerable person which might fortunate the risk of accusation research to have a CRB check.	Low
Researching /interviewing a distressing topic	Emotional distress to the researcher	Low	• Researcher will adopt a distress management protocol. • Supervisory team will be available for debriefing. • Interview will be dispersed throughout the week to allow for break. • The University of Nottingham support and Wellbeing services are present to help with any distress issues.	Low
	Emotional distress to the participants	Low	• Research will be trained in communication and interviewing with this kind of participants. • Researcher will adopt a distress management protocol with the participants. • If participants elicit any signs of distress, interview will be discontinued for a break or ended at all. • Research participants will be advised to approach their care team and supportive services if distress persists.	Low
Researching outside the university setting /Public places/ travel	Increased exposure to risks of everyday life and social interaction such as ;			
	Fire	Low	Fire escape Exists will be determined and observed prior to interview.	Low
	Road accidents	Low	Commitment with traffic rules and laws will be adopted. Only licensed cars will be used	Low
	Unpredictable weather conditions	Low	Researcher will wear suitable clothes to the weather conditions.	Low
	Abuse/Bulling	Low	• Researcher will be trained to avoid confrontations and not responds to verbal threats. • Arrangements will be made with supervisors to be aware of the place and time of interviews.	Low
	Loss / theft of personal properties/ research data	Low	• Researcher will be trained to keep valuable items/ money/mobile phone / audio recorder out of sight. • Any loss or theft issues will be reported to the responsible authority.	Low

Individual Vulnerability Questionnaire
COVID-19

Please answer all the questions honestly. The purpose of this questionnaire is to try to minimise the risk to you during the COVID-19 pandemic and to calculate the level of risk for you undertaking clinical placement.

The information you provide will help occupational health to determine whether you are Low Risk, Moderate Risk, High Risk or Very High Risk on clinical placement during the pandemic.

Occupational health uses a tool called COVID Age that helps assess a person's vulnerability to COVID-19. To calculate your COVID Age, you start with your actual age and then add or subtract according to factors such as gender, ethnicity and Body Mass Index (BMI). Ethnicity is included because there is evidence that black, Asian and minority ethnic (BAME) people have increased morbidity and mortality from COVID-19.

If you have any underlying health conditions, occupational health will adjust your COVID Age accordingly. For those students identified as being at higher risk, the tool may trigger your Programme Director to refer you to occupational health for a consultation.

First name:	Ahmed		**Surname:**	Sharaf	
Course:		**Date of birth:**		**Mobile no:**	

Calculate your COVID age		**No. of years to add/subtract from age**	
Sex:	Male Female	No change – 8 years	
Ethnicity:	Asian or Asian British Black Mixed Other non-white White	+ 5 years + 6 years + 5 years + 3 years No change	
BMI (see link below):	Under 30 30 - 34.9 35 - 39.9 ≥ 40	No change + 4 years + 5 years + 10 years	
Covid Age without health conditions:			
1. Are you pregnant?			If yes, Programme Director to refer student to OH
2. Do you have a 'shielding letter' or a shielding condition?			If yes, Programme Director to refer student to OH
3. Do you have any of these health conditions:	• Diabetes • Heart disease • Immune therapy or immune disorder • Kidney disease • Liver disease • Neurological problems • Respiratory disease including asthma		If yes, Programme Director to refer student to OH
Signature:		**Date:**	**24th Sept 2020**

* To calculate your BMI, use this online tool: https://www.nhs.uk/live-well/healthy-weight/bmi-calculator/

OHWorks Head Office
3 Oaten Hill Place
Canterbury CT1 3HJ

www.ohworks.co.uk
01227 286288
info@ohworks.co.uk

OHWorks Limited
Registered In England No: 05919009
Registered Office: 19-21 Swan Street
West Malling, Kent ME19 6JU

SEQOHS

14.05.20

Research site logo anonymous

NHS Trust

INDIVIDUAL RISK ASSESSMENT

Should be used in conjunction with Workplace Assessment when completing Risk Assessment Template Appendix 2

General Information			
Staff Member's Name(s):	Ahmed Sharaf	**Job Title:**	PhD student
		Assignment Number:	
Line manager		**Managers' job title**	
Location / Ward / Area:	University of Nottingham	**Working hours:**	
Date of Assessment:	16/06/2020	**Review date:**	

Identification of Risk Factors affecting COVID AGE			
Individuals underlying health condition category / other risk factors:	*Please insert score next to appropriate boxes:*		COVID AGE (*years to add to age*)
	Staff Member Age:		*Age at last birthday*
	BAME Backgrounds		*Asian or Asian British + 5* *Black +6* *Mixed +5* *Other non-white +3*
	Diabetes		*Controlled with medication +4* *Uncontrolled +10*
	Chronic Lung Disease *Excluding Asthma*		+7
	Chronic Heart Disease		+4
	Chronic Kidney Disease		+6
	Asthma (severe requiring corticosteroids in the past year)		+4
	Liver Disease		+5

Research Site Logo anonymous

	Non-haematological cancer		*Diagnosed, 1 year ago +5* *Diagnosed 1-4.9 years ago +2*
	Chronic neurological disease *Includes motor neurone disease, myasthenia gravis, multiple sclerosis, Parkinson's disease, cerebral palsy, quadriplegia, hemiplegia, malignant primary brain tumour and progressive cerebellar disease, NOT including stroke or dementia*		+10
	Spleen disease *E.g. splenectomy, sickle cell disease*		+4
	BMI		*30-34.9 +4* *35-39.9 +5* *≥40 +10*
	Other immune supressing condition *e.g. uncontrolled HIV, Aplastic anaemia*		+6
	Rheumatoid arthritis, Psoriasis, Lupus		+2
	Gender *Female*		-8 ***(for female age REMOVE 8 years from age)***
	TOTAL COVID AGE		*COVID Age will give an indication of risk level*

Assessment	
Risk Factors to Consider in Assessment ***(this is not exhaustive and the additional notes should be used where required)***	**Comments and Controls to reduce risk**
Are you Patient/Service user/Public facing? See Appendix 3	

Research site Logo anonymous

Can you maintain social distancing at work >2m?	Yes	
Availability and use of PPE (in line with NUH Guidance) – consider any factors which may affect the safe use of PPE such as religion or disability	There are no factors that affect use of PPE	
Are there any disability factors which may affect risk?	No	
Travel to and from work – e.g. Use of Public Transport	Use of Public transport – The government advice about social distancing and face covering will be followed	
Do any other risk assessments or adjustments apply which may affect risk?	Non	
Please tick appropriate box:	✓/x	Monitoring / further action:
Do the agreed actions above reduce the risks to the staff member?	✓	Local manager to review and monitor.
Risk assessment indicates a need to redeploy?		See Redeployment flowchart Appendix 2

Any risk assessment should be reviewed at agreed points. This should be done in a co-operative way with manager and staff member. The risk assessment may be reviewed when:

- **The health status of the staff member changes**
- **You have been shielding but have been advised to return to work**
- **The demands of the role change**
- **The work environment changes**
- **The staff member expresses a concern**
- **Ward starts to admit COVID-19 patients**

Please note this list is not exhaustive

Additional notes

Please add any additional notes as appropriate following discussion. Appendix 1 can be used as an additional template if required. Please include any conclusions here such as staff member declining to proceed with risk assessment:

The role of the above mentioned students is conducting a research interview with research participants and the interviews were now considered mainly through online or telephone interview to ensure safety of both the student researcher and research participants.

Individual's signature (can be electronic signature or reference to email confirmation)		**Date signed**	16/06/2020

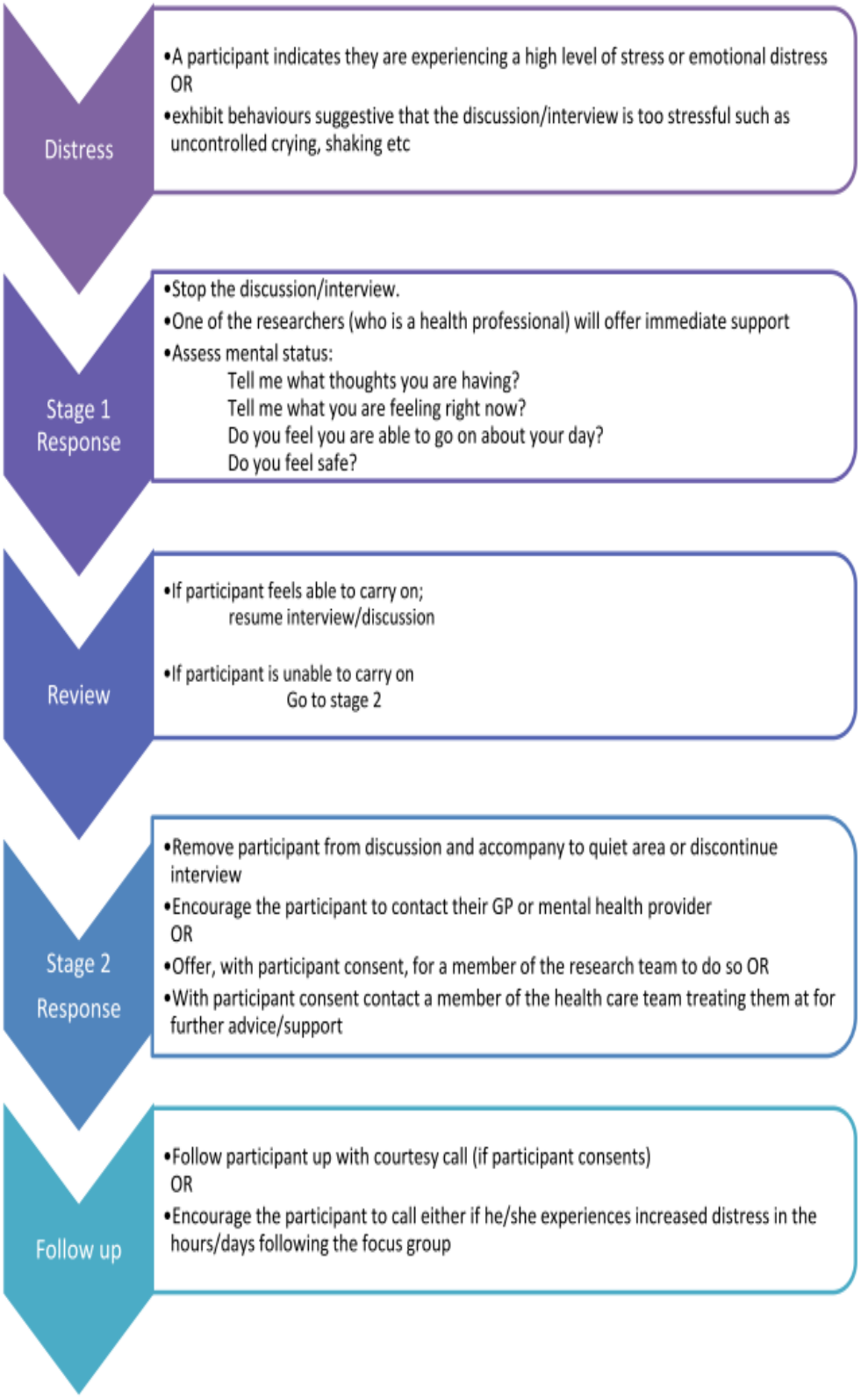
Research site Logo anonymous

Print Name			
Line Manager's signature (can be electronic signature or reference to email confirmation)		**Line Managers job title**	
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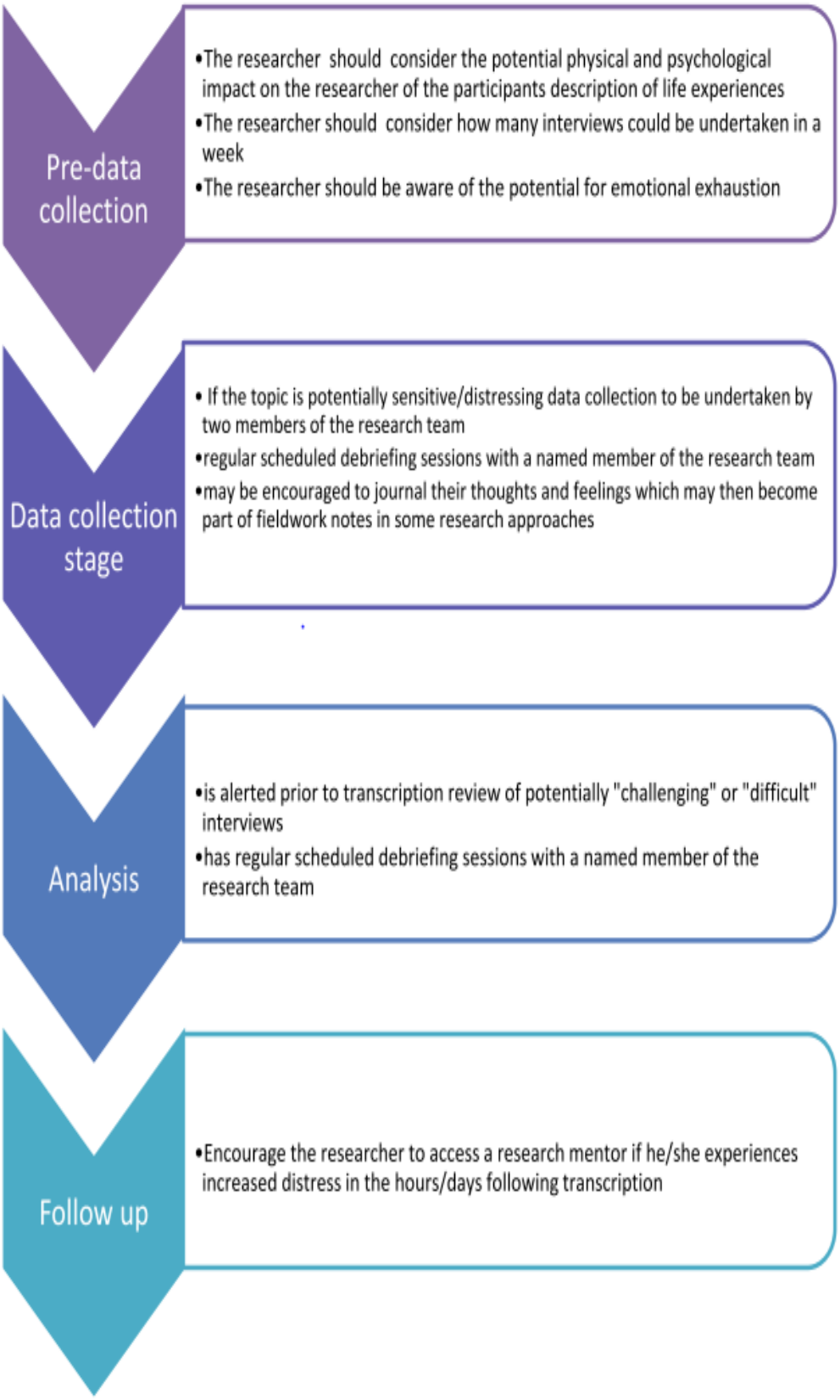
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Appendix 7. Distress protocols

(1) Managing research interview related distress for Participant adopted from Haigh and Witham (2015)



(2) Managing research interview related for researcher adopted from Haigh and Witham (2015)



Appendix 8. Quality assessment using the framework for assessing qualitative evaluation tool

	Appraisal questions	Quality indicators (possible features for consideration	Study evaluation notes
Findings	1.How credible are the findings?	• Findings/conclusions are supported by data/study evidence. • Findings/conclusions 'make sense'/have a coherent logic. • Findings/conclusions are resonant with other knowledge and experience (peer/member review) • Use of corroborating evidence to support or refine findings.	In the findings Chapter five direct participants' quotes were used to illustrate different properties and relationships between major categories of the proposed theory. Preliminary findings and analytical ideas were regularly discussed with supervisory team who had extensive expertise in family caregiving research, and it was apparent that findings were resonating with their experience. However, it was not possible to do member checks due to ethical concerns of distressing FCs. The use of the grounded theory approach and qualitative research skills such as, summarising, and reflection facilitated checking analytical ideas originated through interviews with the subsequent ones. This allowed for flexible adaptation of interview questions and refine data collection activities according to plausible analytical directions.

	1. How has knowledge/ understanding been extended by the research?	• Literature review summarising knowledge to date/key issues raised by previous research. • Aims and design of study set in the context of existing knowledge/ understanding; identifies new areas for investigation. • Credible/clear discussion of how findings have contributed to knowledge and understanding. • Findings presented or conceptualised in a way that offers new insights/alternative ways of thinking. • Discussion of limitations of evidence and what remains unknown/unclear or what further information/research is needed.	Chapter three discussed existing literature and identified research gaps which gave the direction to this study. Chapter six discussed proposed theory regarding the different theoretical models and original research comparable to this study. Chapter seven discussed study aim and objectives regarding the developed categories. It illustrated the study contribution to the knowledge and proposed policy, practice education and research implications. It also discussed strengths and limitations of the study which offers directions for future research.

	3. How well does the evaluation address its original aims and purpose?	• Clear statement of study aims and objectives, reasons for any changes in objectives. • Findings clearly linked to the purposes of the study. • Summary or conclusions directed towards aims of study. • Discussion of limitations of study in meeting aims.	Aim and objectives were discussed in Chapter three and revisited in Chapter seven to illustrate their relationship to findings. Study concluding thoughts in Chapter seven provided answers to study's aim and objectives and reported study limitations.

	4.Scope for drawing wider inference – how well is this explained?	• Discussion of what can be generalised to wider population from which sample is drawn/case selection has been made. • Detailed description of the contexts in which the study was conducted to allow applicability to other settings/contextual generalities to be assessed. • Discussion of how hypotheses/ propositions/findings may relate to wider theory; consideration of rival explanations. • Evidence supplied to support claims for wider inference. • Discussion of limitations on drawing wider inference (e.g., re-examination of sample and any missing constituencies:	Study inferences were made general for FCs of PwC at EoL. The context of study was made clear regarding the place, time and social environment and their impact (e.g., Emergence of the COVID pandemic and its impact on the study process in Chapter four). This impact also resonated in FCs' experiences in findings chapter. Participants' characteristics were mentioned in Chapter five and social context was discussed in (Appendix 9.) to give the reader an idea about the study context. The proposed theory was discussed in relation to other caregiving, role transition, positive and negative aspects of caregiving theoretical models and frameworks. Chapter seven highlighted transferability issues and recommendations for future research.

		analysis of restrictions of study settings for drawing wider inference)	
	5. How clear is the basis of evaluative appraisal?	• Discussion of how assessments of effectiveness/evaluative judgements have been reached (i.e., whose judgements are they and on what basis have they been reached?) • Description of any formalised appraisal criteria used, when generated and how and by whom they have been applied. • Discussion of the nature and source of any divergence in evaluative appraisals. • Discussion of any unintended consequences of intervention, their impact and why they arose.	Formative evaluation of the study was done regularly by the supervisory team and their feedback was taken into consideration. An annual formal peer evaluation of this study was done by an expert in the field regarding the progress of the study and recommendations were followed. Evaluation of the study using this framework was conducted by the researcher. Issues and limitations arose during the data collection process and its consequences were discussed in Chapter four and seven.

Design	6. How defensible is the research design?	• Discussion of how overall research strategy was designed to meet aims of study. • Discussion of rationale for study design. • Convincing argument for different features of research design (e.g. justification for different components or stages of research; methods or data sources etc.) • Use of different features of design/data sources evident in findings presented. • Discussion of limitations of research design and their implications for the study evidence.	A detailed discussion of research design and methods used with justification was provided in Chapter four, while the limitation of the present design was discussed in Chapter seven.

Sample	7. How well defended is the sample design/ target selection of cases/documents?	• Description of study locations/areas and how and why chosen. • Description of population of interest and how sample selection relates to it. • Rationale for basis of selection of target sample/settings/documents. • Discussion of how sample/selections allowed required comparisons to be made.	Chapter four described how the study setting was selected and justified any amendments regarding the settings. It illustrated study participants inclusion criteria and how they have been chosen. Variations in participants' characteristics were considered to allow for comparison regarding their experiences of formal support.

	8. Sample composition/case inclusion – how well is the eventual coverage described?	• Detailed profile of achieved sample/case coverage. • Maximising inclusion (e.g., language matching or translation; specialised recruitment; organised transport for group attendance) • Discussion of any missing coverage in achieved samples/cases and implications for study evidence (e.g., through comparison of target and achieved samples, comparison with population etc.) • Documentation of reasons for non-participation among sample approached/non-inclusion of selected cases/documents.	Access to participants/recruitment methods were discussed in Chapter four. Using different recruitment methods helped in maximising inclusion as possible as explained. FCs' socio-demographic characteristics were reported and reasons for non-participation were highlighted in this chapter. Limitations of the study in Chapter seven explored recruitment issues such as, more male than female participants and limited ethnicity variations and their implications.

		• Discussion of access and methods of approach and how these might have affected participation/ coverage.	

Data collection	9. How well was the data collection carried out?	• Discussion of who conducted data collection and procedures used for collection/recording. • Audio or video recording of interviews (if not recorded, were justifiable reasons given?) • Description of conventions for taking fieldnotes. • Discussion of how fieldwork methods or settings may have influenced data collected. • Demonstration, through portrayal and use of data, that depth, detail, and richness were achieved in collection	Data collection procedure were described in Chapter four where all interviews were audio recorded. Fieldnotes were taken when necessary. Reflections on influencers on the data collection process were described in this Chapter. Participants' quotes were provided to illustrate the quality and comprehensiveness of data in findings Chapter.

ANALYSIS	10. How well has the approach to, and formulation of, the analysis been conveyed?	• Description of form of original data (use of verbatim transcripts.) • Clear rationale for choice of data management method/tool/package. • Evidence of how descriptive analytic categories, classes, labels etc. have been generated and used. • Discussion, with examples, of how any constructed analytic concepts/typologies etc. have been devised and applied.	Chapter four described data sources and analysis and data coding process with justification. It described how the analysis was done and generated the theoretical categories. In findings chapter, each category of the proposed theory was supported by relevant codes and FCs' quotes that shows how each code pertain to categories and theory developed.

	11. Contexts of data sources – how well are they retained and portrayed?	• Description of background or historical developments and social/organisational characteristics of study sites or settings. • Participants' perspectives/ observations placed in personal context (e.g. individual profiles, textual extracts annotated with details of contributors) • Use of data management methods that preserve context (i.e. facilitate within case description and analysis)	Chapter four described social context of the study setting. FCs' characteristics were discussed in findings chapter and FCs' social profiles was reported in Appendix 9. Participants' quotes were attributed to relational context to PwC and social context was described in the commentary when necessary to facilitate understanding of data interpretation and social background attached to it. Using (Nvivo 12) software helped to preserve the context through facilitated return to the original interview whenever needed during the analysis process.

	12. How well has diversity of perspective and content been explored?	• Discussion of contribution of sample design/ case selection in generating diversity • Description and illumination of diversity/multiple perspectives/ alternative positions in the evidence displayed. • Evidence of attention to negative cases, outliers or exceptions • Typologies/models of variation derived and discussed. • Examination of origins/influences on opposing or differing positions. • Identification of patterns of association/linkages with divergent positions/groups.	Purposive maximum variations sampling technique facilitated including FCs with differing characteristics which enriched the diversity aspect of the studied phenomenon that was described in Chapter four. Findings and proposed theory represented varied perspectives and disconfirming cases to the general assumptions and experiences in the study which was discussed in Chapter five while displaying the relationships in the data presented.

	13. How well has detail, depth and complexity (i.e. richness) of the data been conveyed?	• Use and exploration of contributors' terms, concepts and meanings. • Unpacking and portrayal of nuance/subtlety/ intricacy within data • Discussion of explicit and implicit explanations. • Detection of underlying factors/influences. • Identification and discussion of patterns of association/conceptual linkages within data • Presentation of illuminating textual extracts/observations.	Findings chapter described the theoretical concepts developed and relationships between different categories which clarified the nuances of data and interpretations. Including direct participants' quotes and detailed analytical commentaries gave a sense of explicit and implicit meanings of FCs' experiences. Discussion of properties and influencers on developed categories of FCs' experiences were presented in the findings chapter and interpreted in the discussion chapter.

REPORTING	14. How clear are the links between data, interpretation and conclusions – i.e. how well can the route to any conclusions be seen?	• Clear conceptual links between analytic commentary and presentations of original data. • Discussion of how/why particular interpretation/ significance is assigned to specific aspects of data – with illustrative extracts of original data. • Discussion of how explanations/ theories/conclusions were derived – and how they relate to interpretations and content of original data ; whether alternative explanations explored. • Display of negative cases and how they lie outside main proposition/theory/	Chapter four documented analysis process and illustrated how the data was coded and transformed into theoretical categories. Findings chapter discussed the theoretical categories with participants' quotes and showed how the different categories related to each other with a diagrammatic illustration of these relationships. Negative cases were discussed when necessary to illustrate the variations of FCs' experiences that contributed to developed theory.

		hypothesis etc.; or how proposition etc. revised to include them.	
	15. How clear and coherent is the reporting?	• Demonstrates link to aims of study/research questions. • Provides a narrative/story or clearly constructed thematic account. • Has structure and signposting that usefully guide reader through the commentary? • Provides accessible information for intended target audience(s) • Key messages highlighted or summarised.	Chapter seven illustrated the link between the study aim and objectives and the study findings. The participants' quotes and associated commentaries were integrated to provide nuances of data and illustrated the reported category. Signposting was used through the chapter content when necessary and the introduction and summary of each chapter were used. This signposts the reader for the content illustrated and provided a summary of the key messages of each chapter. When necessary, supporting documentation e.g., study approvals etc. was provided in appendices.

	16. How clear are the assumptions/ theoretical perspectives/ values that have shaped the form and output of the evaluation?	• Discussion/evidence of the main assumptions/ hypotheses/theoretical ideas on which the evaluation was based and how these affected the form, coverage or output of the evaluation (the assumption here is that no research is undertaken without some underlying assumptions or theoretical ideas) • Discussion/evidence of the ideological perspectives/values/ philosophies of research team and their impact on the methodological or substantive content of the evaluation (again, may not be explicitly stated)	Reflexivity section in Chapter four illustrated how personal and professional assumptions were considered that might have influenced this study. The study design decisions were discussed and justified in that chapter. Potential biases were always highlighted and discussed during the supervisory meetings and resolved.

		• Evidence of openness to new/alternative ways of viewing subject/theories/ assumptions (e.g. discussion of learning/concepts/ constructions that have emerged from the data; refinement restatement of hypotheses/theories in light of emergent findings; evidence that alternative claims have been examined) • Discussion of how error or bias may have arisen in design/data collection/analysis and how addressed, if at all. • Reflections on the impact of the researcher on the research process.	

ETHICS	17. What evidence is there of attention to ethical issues?	• Evidence of thoughtfulness/ sensitivity about research contexts and participants • Documentation of how research was presented in study settings/to participants (including, where relevant, any possible consequences of taking part) • Documentation of consent procedures and information provided to participants. • Discussion of confidentiality of data and procedures for protecting. • Discussion of how anonymity of participants/sources was protected. • Discussion of any measures to offer information/advice/	Ethical considerations regarding participants' invitation, consenting, interviewing and anonymity and data protection were discussed in Chapter four. Appendix 3. included study documentations such as PIS and informed consent. Training was considered regrading EoL communication, Good Clinical Practice, and informed consent procedures to ensure ethical conduct of the study. Participants were given contacts of support services if needed (Appendix 3.6). The impact of study participation was discussed in Chapter four and protocol for dealing with distressed participants was in place (Appendix 7).

		services etc. at end of study (i.e. where participation exposed the need for these). • Discussion of potential harm or difficulty through participation, and how avoided.	

AUDITABILITY	18. How adequately has the research process been documented?	• Discussion of strengths and weaknesses of data sources and methods. • Documentation of changes made to design and reasons, implications for study coverage. • Documentation and reasons for changes in sample coverage/data collection/analytic approach; implications. • Reproduction of main study documents (e.g., letters of approach, topic guides, observation templates, data management frameworks etc.).	Chapter four discussed data collection methods and methodological related decisions with justification. Chapter seven discussed study's strengths and limitations that included critique and issues regarding data collection process. A copy of participation documents was provided in (Appendix 3).

Appendix 9. Social context of the family carers

FC01: Elizabeth cared for Richard

Richard was (50-55 yrs.), suffering from throat cancer with metastasis. He needed support with Activities of Daily Livings (ADLs) (e.g., dressing) and management of some medical tasks (e.g., wound care). Richard received professional visits from HCPs (e.g., district nurses) and was provided with necessary equipment and aids.

Elizabeth was (60-65 yrs.), married FC who cared for her brother Richard. She was a working FC and had an adult daughter, Elizabeth shared caregiving with her other sister at Elizabeth's house.

FC02: Barbara cared for Margaret

Margret was (60-65 yrs.), had breast cancer for 20 yrs. ago while she was diagnosed with stage IV breast cancer 7 yrs. prior her death. Margert lived alone, and Barbara used to visit / stay with her mother when needed. Margret needed help with household tasks and medication. She was admitted for the last three weeks of her life and died at the palliative care unit which conformed her wishes of preferred place of care and death.

Barbara was (40-45 yrs.) FC who cared for her mother Margaret. Barbara was living with her husband and two stepchildren. She was working while caring for her mother. She got help from her aunt who used to come and help with her Margaret's care.

FC03: Amber cared for Angela

Angela was (55-60 yrs.), had ovarian cancer 16 years ago prior death. Angela lived alone and just needed checking, while did not need help with ADLs. She received HCPs visits (i.e., Macmillan nurses). Angela was admitted to PCU a month prior her dying due to deterioration of her condition, however, this conformed her preferred place for death.

Amber was (25-30 yrs.) FC cared for her mother. She was married and working while she was caring for her mother. Amber used to visit her mother every day and spend the weekends with her.

FC04: Amy cared for Martha

Martha was (60-65 yrs.), had lung cancer three years prior death. Martha was living alone and needed help with ADLs (e.g., personal care), household activities and medications management. She received HCPs' visits (e.g., Macmillan nurses, community nurses and paid carers); she tried night sitting service one time. There was a previous intention for hospice admission. However, this was changed with the emergence of COVID; Martha stayed at home until death.

Amy was (30-35 yrs.) FC cared for her mother Martha. Amy was living with her two children and was working while caring for her mother. Amy and her other sister used to care for Martha interchangeably. After the COVID lockdown, Amy moved to care for her mother and stayed with her until she died.

FC05: Victoria cared for Robert

Robert was (65-70 yrs.) suffered from oesophageal cancer with metastasis two years ago before death. Robert received HCPs' visits (e.g., palliative care nurses, district nurses and GP). He needed help with ADLs, medication, and colostomy care.

Victoria was a (65-70 yrs.) FC cared for her husband Robert. Victoria was a housewife and had two adult children; a son who was staying with her during caregiving of her husband and a daughter who came sometimes to support her. Towards EoL, the care burden increased, and Robert required 24hrs support, thus hospice admission was decided. Victoria was struggling during bereavement, and she was self-referred for counselling.

FC06: Sarah cared for Jessica

Jessica was (65-70 yrs.) had a primary diagnosis of breast cancer 15 yrs. ago. She got a secondary liver cancer with metastasis at the age of 60+. Jessica needed help with ADLs (e.g., feeding, washing etc) and social companionship. She received HCPs' visits (e.g., Macmillan nurses, paid carers, district nurses and GP). She also received equipment and aids and night sitting services.

Sarah was (45-50 yrs.) FC cared for her mother Jessica. Sarah was working while caring for her mother. She was living with her husband and her child while caring for her at mother's home. Sarah shared caring with her step farther and her other two sisters.

FC07: Jennifer cared for William

William was (55-60 yrs) was diagnosed with oesophageal cancer seven yrs. prior dying. He was cared for at home until he was admitted for surgery and died at the hospital. William needed help in ADLs and medication. He received HCPs visits (e.g., District nurses, Macmillan nurses and paid carer). He was provided some equipment and aids.

Jennifer was (50-55 yrs) FC cared for her husband. She had two adult children; one of them was staying with her. Jennifer was working throughout her husband's illness but had a leave when he deteriorated in the last two months. She got help from her siblings in caring for her husband.

FC08: Emily cared for Jean

Jean was (70-75 yrs.) had pancreatic cancer that rapidly progressed. She died within two months post diagnosis at home. She needed help in ADLs and received HCPs' visits (e.g., Macmillan nurses).

Emily was (60-65 yrs.) FC cared for her mother Jean. She was married and had adult children and lived in another city. Emily shared the care with her other three siblings and stepfather. She was working during her mother's illness, but she used to visit and care for her every weekend. Emily got a leave to stay with her mother at the last week of her life.

FC09/FC10: Amanda and Heather cared for Mark

Mark was (65-70 yrs.) had lung cancer a year ago that metastasized to the brain and lymph nodes. Mark was being cared for at home. However due to increased care burden, he was admitted to the hospice in the last two weeks of his life. Mark needed help with ADLs and received HCPs' visits (e.g., paid carers, palliative care nurses, district nurses). He also received some night sitting services.

Amanda was (35-40 yrs.) married FC cared for her father. She shared the care with her mother 'Heather'. She was working and had childcare responsibilities while she was caring for her father. She used to visit her father daily throughout his illness to support her mother in caring for Mark.

Heather was (70-75 yrs.) FC cared for her husband 'Mark'. Heather was a housewife. She suffered from some health problems e.g., rheumatoid arthritis and fibromyalgia while she was caring for her husband. Heather received psychological counselling.

FC11: Maria cared for Thomas

Thomas was (50-55 yrs.) suffered from prostate cancer with metastasis four years ago prior dying. Thomas needed help with ADLs and medication management. Thomas received HCPs' visits (e.g., paid carers, community nurses, palliative care nurses, and GP).

Maria was (55-60 yrs.) FC cared for her husband Thomas. She was a housewife and had no children. Maria received psychological counselling.

FC12: Natalie cared for Albert

Albert was (45-50 yrs.) had oesophageal cancer six months prior dying at home. Albert needed help with ADLs and received phone consultations from palliative care team and HCPs' visits (e.g., Macmillan and district nurses). He also received some sitting services (Hospice at home), nutritional advice and support and was issued some equipment and aids.

Natalie was (50-55 yrs.) FC cared for her husband Albert. She was a mother of five children and was working while caring for her husband. Natalie received psychological counselling.

FC13/FC14: Olivia and Debra cared for Ann and Rachel

Ann was (75-80 yrs.) had lung cancer one-month prior death that metastasized to the brain, and she died at home. Ann needed help for

ADLs and received HCPs' visits (e.g., district nurses, paid carers), night sitting services and some equipment and aids.

Rachel was (55-60 yrs.) had breast cancer with metastasis. Rachel aimed to be cared at the hospice. However, the COVID changed her preferences and she wanted to stay at home. Rachel needed help with ADLs. She received HCPs' visits (district/community nurses, palliative care nurses and paid carers) and was issued some equipment and aids.

Olivia was (60-65 yrs.) FC cared for her mother Ann and her sister Rachel. Olivia was married and working while she was caring for her mother and sister. Olivia had multiple siblings and nieces who formed an informal care team for Ann and Rachel. Olivia relied on wellbeing centres for advice and received bereavement counselling after her sister death.

Debra was (35-40 yrs.) FC cared for her grandmother 'Ann' and her aunt 'Rachel'. Debra had children's responsibilities and was working while caring.

FC15: Laura cared for Susan

Susan was (70-75 yrs.) had pancreatic cancer six months prior to death. she was cared for at home for seven weeks then she was admitted to the hospice for control of symptoms for the last nine weeks and died there. Susan needed help with ADLs and provision of medications. She received HCPs' visits (e.g., paid carers and occupational therapist), nutritional advice and support and some equipment and aids.

Laura was (40-45 yrs.) FC cared for her mother Susan. Laura was doing a PhD while caring for her mother, but she took a leave to care for her mother. Laura was signposted to financial support and received counselling. She received hospice phone advice and drop-in sessions for information.

FC16: Stephanie care for Sophia

Sophia was (60-65 yrs.) had secondary brain cancer. She moved to her daughter's house to be cared for where she died. Sophia needed help with ADLs and medications. She received HCPs' visits (e.g., doctors,

district nurses, paid carers, palliative care nurses, occupational therapists), night/day sitting services and some equipment and aids.

Stephanie was (40-45 yrs.) FC cared for her mother Sophia. She was a mother of two children. Stephanie was working until she brought her mother home, then took a care leave. She received help from her husband in caring, and she received psychological counselling.

FC17: Daniel was caring for Linda

Linda was (50-55 yrs.) and diagnosed with pseudomyxoma peritonei nine years ago. Lina was admitted to the hospice for symptoms management, and it was planned to be discharged with few days. However, she wanted to die at the hospice. Linda needed help in ADLs (e.g., personal care), household tasks, stoma care and she was on total parenteral nutrition. She received HCPs' visits (e.g., paid carers, district nurse, stoma nurses, occupational therapist).

Daniel was (40-45 yrs.) FC was caring for his wife Linda. He was working while caring for his wife and received help from his father and his sister.

FC18: Donald was caring for Christine

Christine had (70-75 yrs.) had secondary lung cancer. Linda wishes to spend the last period of her life at the hospice. Her caring needs were minimal, and only need help with household tasks.

Donald was (65-70 yrs.) retired FC who was caring for his wife Christine. They had an adult son who did not live with them, but he used to help them whenever needed.

FC19: George cared for Teresa

Teresa was (80-85 yrs.) had liver cancer for about two years. She needed help with ADLs and received HCPs' visits (e.g., paid carers). However, she was admitted to the palliative care unit towards EoL where she died.

George (80-85 yrs.) retired FC cared for his wife Teresa. He has four adult children, he received help from his daughter in caring for his wife.

FC20: Abigail cared for Jack

Jack was (70-75 yrs.) had lung cancer about two years ago. Jack needed help with ADLs. He received HCPs' visits (e.g., paid carers, district nurses, and Macmillan nurses). However, he needed 24 hrs care towards EoL, so that he was admitted to a care home.

Abigail was (45-50 yrs.) FC cared for her father Jack while being at home. She was working while caring, and her role was mainly to check on him and make sure that he attended his medical appointments and medication.

FC21: Christina cared for Matthew

Matthew was (55-60 yrs.) had renal cancer one year prior his death. Mathew was cared for at home. He was admitted to the hospice for only one night where he died. Mathew needed help with ADLs and received HCPs' visits and calls (e.g., Consultant phone calls, district nurses' visits, palliative care nurses, and community carers) and some equipment and aids.

Christina was (60-65 yrs) FC cared for her husband Matthew. Christina was working and then went in furlough scheme during the COVID lockdown. However, she left work when her husband cancer diagnosis was confirmed as untreatable to care for him. Christina was offered psychological counselling.

FC22: Marilyn cared for Andrew

Andrew was (70-75 yrs.) had melanoma three years prior to his death. He needed support in ADLs and some medical tasks (e.g., Wound care, vital signs monitoring and medication management). Andrew received HCPs' visits (e.g., District nurses). He was admitted to the hospice in the last week of his life.

Marilyn was (70-75 yrs.) FC cared for her husband Andrew. She was housewife and only her brother helped her in caring for her husband. Marilyn received psychological counselling.

FC24: Doris cared for Patricia

Patricia is (85-90 yrs.) was diagnosed with bowel cancer four years ago. The cancer metastasised to her liver and her lung, and she also suffered from osteoarthritis. Patricia lived alone and needed help with ADLs. She received a range of support services such as HCPs' visits (e.g., Clinical nurse practitioner, paid carers visits) and continent care, podiatry care, occupational therapy and some equipment and aids.

Doris is (55-60 yrs.) retired FC who was caring for her mother Patricia. She suffers from multiple health problems (e.g., Fibromyalgia, spinal cyst and mobility problems) that restricted her ability to care for her mother. Doris had support from her daughter while caring for her mother. She used to get support from the wellbeing centre, and she offered a contact for carer support organization.

FC25: Carolyn cared for her brother Eric

Eric is (60-65 yrs.) was diagnosed with renal cancer about eight years ago. He lives alone and needed help with ADLs. He received HCPs' visits (e.g., Macmillan nurses and paid carers), and equipment and aids. Eric was admitted to palliative care unit after deterioration.

Carolyn was (60-65 yrs.) FC who was caring for her brother Eric. She was married and working while caring. She shared the care of her brother with her other sister. She also was supporting her husband who was diagnosed with bone marrow cancer. Carolyn was offered complementary therapy sessions.

FC26.1/ FC26.2: Rose and Frank cared for Brian

Brain was (60-63 yrs.) had stage IV bowel cancer with metastasis to liver about 15 months prior his death. Brian was quite independent until died and only needed social companionship and checking at home. Brian received HCPs' visits (e.g., Palliative care nurses and district nurses) and some equipment and aids.

Rose and frank were a married couple who cared for their friend Brain at his home. Rose is (60-65 yrs.) FC, was working while caring for her friend, while Frank was (55-60 yrs.) retired FC. Rose used Macmillan cancer telephone support for emotional support.