

**Distance caregiving in palliative care:
a mixed methods study exploring the role of
ehealth**

This thesis is submitted in partial fulfilment of the requirements of the award
of

Doctor of Philosophy

By

Carolina Casañas i Comabella

Faculty of Health and Life Sciences

Oxford Brookes University

September 2017

*How people die remains in the memory of
those who live on.*

Dame Cicely Saunders

Abstract

Background: There are an estimated 500,000 family carers in the UK providing care to a relative near the end of life. While the needs of local caregivers have received considerable attention, little is known about those who provide care from a distance. This PhD aimed to explore how distance shapes caregiving in palliative care, and how distance caregivers use ehealth.

Methods: A mixed methods design was used. Survey participants were recruited through social media and hospice staff. The questionnaire comprised sections about: relationship and distance; use of Information and Communication Technologies (ICT); the Hospital Anxiety and Depression Scale (HADS); and the Family Inventory of Needs (FIN). A subgroup of questionnaire respondents were interviewed; these data were analysed using Framework Analysis. The two methodologies captured complementary aspects of distance caregiving.

Results: Survey responses were obtained from 79 participants (87% responded online). Distance caregivers were commonly women of middle age in paid work providing care to a parent. 93.2% reported that they used ICT in their role as caregivers; 86.6% found that helpful. Twenty-one survey respondents in eight countries were interviewed via telephone, Skype® or FaceTime®, and were asked about their experience of distance caregiving, and their use of ICT as carers. Three themes were identified: *Connectedness* showed that the deep emotional connection between the caregiver and the patient remained intact despite the distance; *Uncertainty* looked at how distance added further uncertainty to the caregiving experience in palliative care; and *Psychological Struggle* examined the emotional conflict experienced by distance caregivers, who felt their lives were divided in two different worlds. Participants used ICT in a variety of ways to overcome distance.

Conclusions: Distance caregiving in palliative care is a complex phenomenon that has received little attention from researchers and policy makers. Findings from this study indicate the need for future research to determine a universal definition of distance caregiving, to ensure that these carers are identified in clinical settings and receive appropriate support. The applications of ehealth in palliative care distance caregiving need to be explored.

Acknowledgements

Anyone that has done a PhD knows that it is a crazy journey with more downs than ups. This PhD, like most are, has been a wild ride, and I have a lot of people to thank for their support.

I would like to thank my supervisors Prof Mary Boulton, Prof Eila Watson and Prof Bee Wee for their advice and for allowing me the freedom to make this PhD my own. Prof Wee's tireless efforts to improve the provision of palliative and end of life care have been a constant source of inspiration for years and I am lucky to call her my supervisor.

Thank you to my family and friends who have always been supportive and encouraging; my sister and my mother have been cheerleading me all the way during the final months. Dr Monica Hadi's wise words have always been reassuring and showed me that this could, in fact, be done. Thank you to everybody who kindly proofread chapters of this dissertation, including Nick Pothecar.

The best part of my PhD was, without a doubt, sharing it with my PhD friends and colleagues Dr Marta Wanat, Dr John Curtin, and Dr Vic Coathup. We have shared so many laughs, tears and hugs. This would have been so much more difficult without you and I am so lucky to have met you and your families.

I would also like to thank my champion recruiters Dr Bridget Taylor and Dr Kat Naessens, who tirelessly looked for patients who had distance caregivers and informed them of my study. Seeing how much you believed in my study when very few people cared about it was a huge boost and I will be forever grateful. Annette Honeywell and Michelle Holgate at Oxford Brookes University provided caring support and advice when I needed it and their help made a difference to my wellbeing during this PhD.

The biggest thank you goes to my life-long partner John Pilbeam. Your endless patience and unconditional support every single day of this long journey have carried me over to the other side of the PhD tunnel and I have no words to describe how much I love you. You are the light of my life.

Finally, I need to thank all the participants who kindly shared their experience of caring from a distance. You not only generously donated your time to my project by filling out the questionnaire; those of you whom I interviewed opened your hearts and shared difficult experiences, sometimes for the first time. As all work in palliative care, it was so humbling and I feel privileged that you let me listen to your caregiving journey. During the lowest moments of this PhD when I felt like giving up, my sense of debt and duty towards you was the only motivation that kept me going. This thesis is for you.

Contents

Abstract.....	2
Acknowledgements.....	2
Abbreviations and acronyms	11
Common definitions.....	12

Chapter 1: General introduction

1.1. General introduction.....	14
1.2. Family carers in palliative care.....	15
1.3. Distance caregiving	15
1.4. Ehealth	16
1.5. Aims and research questions	17
1.6. Thesis overview.....	17
Chapter 1: General introduction and thesis overview.....	17
Chapter 2: Distance caregiving in palliative care	17
Chapter 3: Ehealth in palliative care	17
Chapter 4: Methodology and methods.....	18
Chapter 5: Findings from the survey.....	18
Chapter 6: Findings from the qualitative interviews	18
Chapter 7: Discussion and conclusions	18

Chapter 2: Distance caregivers in palliative care

2.1. Chapter overview.....	19
2.2. Family caregiving.....	19
2.2.1. Definitions and conceptual frameworks	19
2.2.2. The burden of family caregiving	20
2.3. An overview of distance caregiving	21
2.3.1. Definitions of distance caregiving	22
2.3.2. Characteristics of the distance caregiver	23

2.3.3.	Care provided by distance caregivers	24
2.3.4.	Employment and financial impact of distance caregiving	25
2.4.	Palliative care	26
2.4.1.	A brief introduction to palliative care	26
2.4.2.	Family carers in palliative care	28
	The role of the family in palliative care	29
	What family carers in palliative care do	30
	The needs of family carers in palliative care.....	31
	Positive aspects of family caregiving in palliative care	33
2.5.	Literature review: Distance caregiving in palliative care	34
2.5.1.	Methods	34
2.5.2.	What do we know about distance caregiving in palliative care?.....	35
2.6.	Chapter summary.....	38

Chapter 3: Ehealth in palliative care

3.1.	Chapter overview	40
3.2.	The paradigm of ehealth.....	40
3.2.1.	Social media in healthcare	42
3.2.2.	The Web 2.0	42
3.2.3.	Barriers to the adoption of ehealth	43
3.3.	The use of ehealth in palliative care	44
3.3.1.	Literature review.....	44
3.3.1.1.	Methods.....	45
3.3.1.2.	Results from the literature review	46
3.3.1.3.	Quality appraisal of the included publications	54
3.4.	Summary of this chapter.....	57

Chapter 4: Methodology and methods

4.1. Chapter overview	59
4.2. Study design	60
4.2.1. Mixed methods research	60
4.2.2. Mixed methods research in palliative care	62
4.2.3. Rationale for choosing a convergent parallel mixed methods design	63
4.2.4. How mixed methods were used in this study	63
4.3. Population of interest	65
4.3.1. Target population	65
4.3.2. Inclusion and exclusion criteria	65
4.4. Identification and recruitment of participants	66
4.4.1. Ethics and Research Governance	66
4.4.2. Recruitment of research participants through PICs	67
4.4.3. Recruitment of research participants through the community	69
4.4.4. Recruitment of research participants through social media	69
Using social media to recruit in palliative care	70
4.4.5. Recruitment for the interviews	72
4.5. Methods of data collection	72
4.5.1. Quantitative methods: questionnaires	72
4.5.1.1. Development of the questionnaire	72
4.5.1.2. The Hospital Anxiety and Depression Scale (HADS)	73
4.5.1.3. Family Inventory of Needs (FIN)	74
4.5.1.4. Versions of the questionnaire	75
4.5.1.5. Cognitive interviews	76
4.5.1.6. Strengths and limitations of the use of questionnaires	76
4.5.2. Qualitative methods: semi-structured interviews	77
4.5.2.1. Development of the interview topic guide	78
4.5.2.2. Strengths and limitations of using semi-structured interviews	79

4.6. Methods of data analysis and synthesis	80
4.6.1. Analysis of quantitative data: descriptive statistics.....	80
4.6.2. Analysis of qualitative data: framework analysis.....	81
4.6.3. Mixed methods: combining the qualitative and quantitative data	87
4.7. Chapter summary.....	87

Chapter 5: Survey results

5.1. Chapter overview	89
5.2. Sample characteristics	89
5.2.1. Characteristics of patients	92
5.2.2. Distance caregiver's relationship to local carers	95
5.3. Distance from the patient.....	97
5.4. Anxiety and depression in distance caregivers.....	100
5.5. The needs of distance caregivers.....	100
5.6. Use of ICT	105
5.6.1. Frequency of use and device used.....	105
5.6.2. Distance caregivers' use ICT in their role as carers.....	106
5.6.2.1. Use of ICT for information	106
5.6.2.2. Use of ICT as an aid to communicate from a distance.....	107
5.6.3. How helpful ICT was.....	109
5.7. Chapter summary.....	110

Chapter 6: Interview findings

6.1. Chapter overview	112
6.2. Sample characteristics	112
6.3. Overarching themes.....	117
6.3.1. Connectedness.....	117
6.3.1.1. Feeling connected to the patient despite the geographical distance	118
6.3.1.2. Providing care from a distance	128

6.3.1.3. Needing to “be there in person”	136
6.3.2. Uncertainty	137
6.3.2.1. Uncertainty about how the patient “is really doing”	138
6.3.2.2. Uncertainty about travelling	141
6.3.2.3. Uncertainty about time left	142
6.3.3. Psychological struggle	143
6.3.3.1. The emotional impact of providing care from a distance.....	143
6.3.3.2. Contrast between two separate worlds	145
6.3.3.3. Positive aspects of caring at a distance	145
6.3.3.4. Guilt.....	146
6.3.3.5. Needing support as distance caregivers	147
6.4. Chapter summary.....	149
 Chapter 7: Discussion and conclusions	
7.1. Chapter overview.....	152
7.2. Discussion.....	152
7.2.1. Key findings	152
7.2.1.1. The need for a definition of distance caregiving	152
7.2.1.2. What this PhD adds to this field of knowledge	154
7.2.2. Limitations and lessons learnt	164
7.2.2.1. Recruitment strategy	164
7.2.2.2. Small sample size	166
7.3. Conclusions	166
7.3.1. Implications for policy and practice.....	168
7.3.2. Recommendations for future research.....	169
References	171

Appendices

Appendix 2.1. Search strategy	185
Appendix 2.2. Characteristics of the articles included in the literature review about distance caregiving	186
Appendix 3.1. Search Strategy	187
Appendix 3.2. Quality appraisal tools	189
Appendix 3.3. Flowchart of inclusion process	198
Appendix 3.4. Characteristics of the articles included in the literature review about ehealth.....	199
Appendix 4.1. Letters of ethics approval from FREC	203
Appendix 4.2. Letters of ethics approval from NRES	204
Appendix 4.3. Poster advertising the study	206
Appendix 4.4. Leaflets for professionals and for patients	207
Appendix 4.5. Invitation letters for potential participants	213
Appendix 4.6. The paper version of the questionnaire	217
Appendix 4.7. Screenshots of the online version of the questionnaire	231
Appendix 4.8. The interview topic guide	235
Appendix 4.9. Consent form	236
Appendix 4.10. Participant Information Sheet	237

Tables

Table 4.1: Characteristics of PICs.....	67
Table 4.2: Channels used to advertise the study in local communities.....	70
Table 5.1: Sample characteristics of survey respondents.....	90
Table 5.2: Patients' characteristics	95
Table 5.3: Activities where the patient needs support.....	93
Table 5.4: Local carers.....	96
Table 5.5: Distance and difficulty to visit	99
Table 5.6: HADS scores	100
Table 5.7: FIN overall scores	101
Table 5.8: FIN: five most important needs	102
Table 5.9: FIN: five least important needs.....	102
Table 5.10: FIN: five most met needs	103
Table 5.11: FIN: five least met needs.....	103
Table 5.12: Frequency of use	104
Table 5.13: Devices used.....	106
Table 5.14: Single device versus multiple device.....	106
Table 5.15: Use of ICT to seek information online.....	107
Table 5.16: How distance caregivers keep in touch with their relative.....	108
Table 5.17: How distance caregivers communicate with the medical team	109
Table 5.18: How helpful ICT was in carer role	110
Table 6.1: Characteristics of people interviewed	113

Figures

Figure 1.1: The three core elements of this thesis.	14
Figure 4.1. How a convergent mixed methods design was used in this PhD.	64
Figure 4.2: The recruitment process through PICs.	69
Figure 4.3: The five stages of framework analysis (Ritchie & Spencer 1994).....	82
Figure 6.1: The three overarching themes.....	117
Figure 7.1: The three elements that a definition of distance caregiving should encompass.	154

Abbreviations and acronyms

CASP	Critical Appraisal Skills Programme
CONSORT	Consolidated Standards of Reporting Trials
CSNAT	Carer Support Needs Assessment Tool
EAPC	European Association for Palliative Care
FCA	Family Caregivers Alliance
FIN	Family Inventory of Needs
FREC	Faculty Research Ethics Committee
HADS	Hospital Anxiety and Depression Scale
HRA	NHS Health Research Authority
ICT	Information and Communication Technologies
MND	Motor Neuron Disease
MORECare	Methods Of Researching End of life Care
MRC	UK's Medical Research Council
NCPC	National Council for Palliative Care
NRES	NHS Research Ethics Service
PIC	Participant Identification Centres
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROM	Patient-Reported Outcome Measure
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organisation

Common definitions

Carer/Caregiver

A carer is a family member who provides any kind of meaningful support to a relative in need. Such support can be instrumental (e.g. bathing, feeding, giving medication), emotional (e.g. listening to worries and concerns, either in person, over the telephone or via post/email), information-oriented (e.g. clarifying the treatment or process of the disease, explaining what advance directives are), financial (e.g. contributing to the costs of formal, paid care or equipment), organisational (e.g. employing someone else to provide the practical care), and any other activities that involve any kind of significant support. In this thesis, the terms carer and caregiver are used interchangeably.

Distance caregiver

For the purposes of this study, a distance caregiver was defined as a family carer who is restricted in how often they can visit because they do not live nearby.

Ehealth

“The use of information and communication technologies (ICT) for health. Examples include treating patients, conducting research, educating the health workforce, tracking diseases and monitoring public health.” (World Health Organisation, 2015)

Authors have referred to this term as ‘eHealth’, ‘e-health’ or ‘ehealth’. This thesis will use the ehealth spelling.

End of life care

The General Medical Council (GMC) defined patients who are approaching the end of life as those *“likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months.”* (General Medical Council, 2010)

Palliative care

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [...]. Offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients

and their families, including bereavement counselling, if indicated.” (World Health Organisation, 2014).

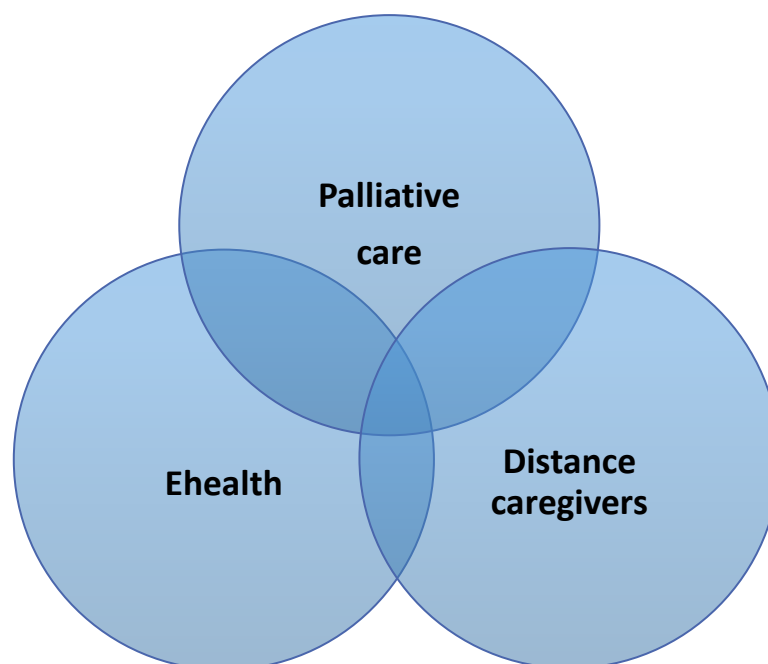
Chapter 1: General introduction and thesis overview

1.1. General introduction

This introductory chapter provides a summary of the background information and rationale for conducting this doctorate. The research questions investigated in this programme of work will be stated and a brief overview of the structure of this dissertation is provided.

This PhD thesis comprises three core elements: palliative care, distance caregivers and ehealth (see Figure 1.1). The next three sections will briefly present each of these components.

Figure 1.1: The three core elements of this thesis.



1.2. Family carers in palliative care

Looking after those who are dying is at the core of medicine (Callahan, 2000). The World Health Organisation (Worldwide Palliative Care Alliance, 2014) recently estimated that over 29 million people died in the world in 2011 who required palliative care. The largest age proportion (94%) corresponded to adults, of which over 69% are over 60 years old (Worldwide Palliative Care Alliance, 2014). In England, it is estimated that in England around half a million people provide care at home to someone who is near the end of life (NHS England, 2014).

The aim of palliative care is to improve the quality of life of patients and their families facing a life-threatening illness (World Health Organisation, 2014). Family carers are an integral part of the patient's care, and it is widely recognised in palliative care that they are instrumental in providing support to the patient (Department of Health, 2008). The role of these carers has received considerable attention in research (Hudson & Payne, 2009; Hudson et al., 2010a; Payne, 2010b; Payne & Grande, 2013), and their support needs have been examined and recognised (Department of Health, 2008; National Council for Palliative Care, 2013).

Family carers in palliative care face unique challenges, including coping with the patient's deterioration and needs, and this impacts on their own psychological and physical health, their social activities and identity, their work and finances (Payne, 2010a). Further, family caregiving in palliative care takes place within a set of pre-existing family dynamics, which in turn affect the carer-patient relationship and those around them (Payne, 2010a).

1.3. Distance caregiving

Globalisation during the second half of the 20th century and beginning of 21st century has meant that more and more people are able to, or are forced to, move away from their families of origin, and around 175 million people were living outside of their countries of birth or citizenship at the beginning of the 21st century (Hollifield, 2004). People now may change place of residence seeking study or work opportunities, for sentimental reasons, or due to forced migration (e.g. displaced people due to conflicts, natural disasters, or famine). This flow of migration, whatever the cause, has also impacted on the configuration of families, bringing cultural variations which have a direct impact on care, such as the place of care and death (home vs. institutional), or the different ways of expressing and providing care depending on cultural backgrounds and expectations (Kellehear, 2009). It is now recognised that the current trend towards smaller, dispersed families is affecting the way palliative care is provided (World Health Organisation, 2004). Despite this, most studies about family caregiving in palliative care have generally focused on caregivers who live in the same

household as, or near to, the patient. There is a paucity of evidence about the experiences of people who are geographically far from a relative. Little is known about those who provide care and support from a distance to a relative who has an advanced, life limiting disease in this field. Distance caregivers in palliative care remain a largely invisible population to clinicians, researchers and policy makers.

1.4. Ehealth

Deeply intertwined with the societal changes in the last few decades, breakthrough developments in technology have substantially transformed society: we now live in what has been called the Information Society (Mansell, 2009). The central aspect of the Information Society is the use of Information and Communication Technologies (ICT) to process, share and analyse information, and to communicate instantly despite great distances.

ICT have also affected the way that healthcare is provided and understood, and the ways patients, carers and healthcare professionals interact (Jadad et al., 2003; Powell et al., 2003). Ehealth is a relatively new term coined in the early 21st century that encompasses the use of ICT in healthcare (World Health Organisation, 2015). The term *ICT* refers to the vast array of technologies that are used to communicate and share data instantly and regardless of distance, and can be used in any area, for instance industry or higher education. *Ehealth* focuses on how these technologies are used for healthcare, in a broad sense. Hence, ehealth is an umbrella term that covers the use of ICT for the research, education, delivery and evaluation of healthcare. In summary, ICT refers to the actual group of technologies, which could be applied to any field, whilst ehealth refers to the application of ICT specifically to healthcare.

In the particular landscape of distance caregiving, ICT have the potential to provide ways to reduce the added burden of distance and enabling families to support their loved ones (Benefield & Beck, 2007). A recent systematic review looked at the effectiveness of ehealth interventions in palliative care (Capurro et al., 2014), and highlighted that only a small number of studies have looked at the online information needs of family caregivers in palliative care. The authors recommended that future studies specifically look at the ehealth needs of informal carers (Capurro et al., 2014).

Despite some research conducted around the use of ehealth in palliative care, to date few studies have reported how family carers use ehealth, and none have aimed to explore how distance caregivers use ehealth in palliative care.

1.5. Aims and research questions

The overall aims of this study are to explore how distance shapes the experience of family caregiving in palliative care, and how those who care at a distance use ehealth. The overarching research questions were:

- How does being at a distance shape the nature of family caregiving in palliative care?
- What are the characteristics and experiences of distance caregivers in palliative care?
- What are the needs of distance caregivers in palliative care?
- How do distance caregivers in palliative care use ICT in their role as carers?

1.6. Thesis overview

This section provides a brief overview of the thesis and highlights the main elements of each chapter.

Chapter 1: General introduction and thesis overview

This chapter has presented a brief summary of the rationale for this doctorate, the overall aims and objectives of this thesis and has provided an overview of the structure of this dissertation.

Chapter 2: Distance caregiving in palliative care

Chapter two will provide an overview of different definitions, theoretical frameworks and elements of family caregiving, before focusing on the phenomenon of distance caregiving. It will then examine the challenges that are specific to family caregiving in palliative care, and present the methods and results from a literature review examining the evidence around distance caregiving in palliative care.

Chapter 3: Ehealth in palliative care

This chapter will first present an overview of ehealth, including a brief overview of the social, technological and cultural factors that have facilitated its advent. This will be followed by the methods and results from a literature review around the use and experiences of ehealth by family carers in palliative care.

Chapter 4: Methodology and methods

The methodological approach of this PhD will be discussed, and the theoretical underpinnings of mixed methods will be presented. The chapter will then describe the population of interest for this doctorate, and the methods of data collection: a survey and a set of semi-structured interviews. The last section will explain in detail the methods of data analysis employed in this study.

Chapter 5: Findings from the survey

Chapter five will analyse and present the survey results, including the sample characteristics of both distance caregivers and the recipients of care, the findings around distance (how far away distance caregivers lived, how long it took them to travel to the patient, how difficult this was), and how participants used ICT in their role as carers. The chapter will also analyse the results from the Hospital Anxiety and Depression Scale (HADS) and the Family Inventory of Needs (FIN).

Chapter 6: Findings from the qualitative interviews

This chapter will analyse the findings from the qualitative interviews conducted as part of this study. Participants' experiences of distance caregiving in palliative care will be examined, as well as the way they used ICT to manage these challenges. The chapter will present these through three overarching themes: Connectedness, Uncertainty and Psychological Struggle.

Chapter 7: Discussion and conclusions

The final chapter of this PhD thesis will discuss the findings of the study, integrating the main quantitative and qualitative findings in order to provide a comprehensive and multifaceted understanding of distance caregiving in palliative care. Limitations and lessons learnt will also be discussed. This will be followed by the practice and policy implications, and recommendations for future research.

Chapter 2: Distance caregivers in palliative care

2.1. Chapter overview

This PhD thesis comprises three core elements: palliative care, distance caregivers and ehealth. The present chapter focusses on two of these: distance caregiving and palliative care (see Figure 1.1).

The chapter comprises four main parts. The first section provides an overview of the different aspects of family caregiving from a range of theoretical perspectives. The second section presents the phenomenon of distance caregiving. The third part introduces the field of palliative care and examines the challenges that are specific to family carers in palliative care. Finally, the fourth section presents a literature review of distance caregiving in palliative care.

2.2. Family caregiving

This section will provide an overview of family caregiving in general, without limiting it to palliative care, including a range of definitions and conceptual frameworks about caring.

2.2.1. Definitions and conceptual frameworks

There are a number of definitions of caregiving, originating from varied disciplines such as psychology or sociology.

Some definitions of caregiving imply directly or indirectly that the nature of care is practical. In other words, that caregiving must be a task-oriented, hands-on activity. Most of those definitions come from the field of dementia or elderly care, for instance, the well-known Zarit & Edwards definition of care: *“interactions in which one family member is helping another on a regular basis with tasks that are necessary for independent living”* (Zarit & Edwards, 1999) (p. 334). Other authors have used a broader conceptualisation, such as McCarthy & Edwards (2010) who defined care as *“a set of feelings and a set of activities and resources, concerned with supportive relationships”* (p. 17).

A number of authors have proposed conceptual frameworks for family caregiving. The sociologist J. Tronto (Fisher & Tronto, 1990; Tronto, 1993) distinguished four different dimensions of care. The first one, “caring about”, refers to the feelings of caring about the other person. The second one,

“taking care of”, refers to the actual task of providing care. The third and fourth dimensions are “care-giving” (from the point of view of the carer) and “care-receiving” (from the point of view of the person who is the recipient of the care) (McCarthy & Edwards, 2010). Oyeboode (2003) distinguished between objective and subjective carer burden. The objective burden refers to observable tasks of caregiving, such as bathing, cooking, or driving to the doctors’ appointments, whereas the subjective burden depends on the carer’s emotional and psychological reaction to the care he or she provides.

Caring may take place in different spheres (McCarthy & Edwards, 2010). It can be public, or it can be private (at home); formal or informal, depending on the setting; finally, it can be paid or unpaid. These factors greatly influence the shape and the consequences of the care, both for the person who is providing the care and the person who is receiving it.

Some models of care have been proposed. Pearlin and colleagues (1990) described a theoretical framework focused around the stress from caregiving. In this model, several domains interact: the background and context of the care, that is, the social, cultural and personal aspects of the caregiving situation; the mediators, which can be internal resources, such as coping, and external resources, such as social support; the stressors, which can relate to intra-psychic issues around self-esteem or other psychological aspects from the caregiver, or to the patient’s needs, or to roles such as family roles, the caregiver’s job, or economic burdens; and finally, the outcomes of care, which are around the caregiver’s emotional reactions to the stress of the caregiving situation (Pearlin et al., 1990).

2.2.2. The burden of family caregiving

Recent data indicates that there are 6.5 million carers in the UK, and this figure is expected to rise to 9 million in the next 20 years, with more than half of people expected to become unpaid family carers at some point in their life (Carers UK, 2015). The recent report “Personal Social Services Survey of Adult Carers in England 2014-15” (2015) analysed the results from a national survey of family carers in the UK. The findings from this survey showed that two fifths of carers spend 100 hours or more per week providing care, and that the care recipients were people who had dementia (35%), a physical disability (55%), health problems connected to ageing (39%), a mental health problem (20%), or a learning disability (18%), and that over two thirds said that the person they provided care for was 65 years of age or older (Health and Social Care Information Centre, 2015).

Family caregivers have often been identified as mostly female (58%), and the largest age group is between 50-64 years old (Carers UK, 2015). Studies have indicated that carers provide a wide variety of support, including household chores, supervising the patient, emotional and social support,

transport, financial matters, and personal care, with a parent or parent-in-law being the most common recipient of care (Carers UK, 2015). Further, a recent study reported the findings from a national survey of family caregivers of older adults (Wolff et al., 2016). This study indicated that family caregivers provide care with everyday activities, transport, coordination of care, decision making, and direct healthcare such as administration of medicines and wound care (Wolff et al., 2016).

The impact that caregiving has on the carers has also been documented. The Carers UK report concluded that caregiving has impact on the carer's finances, physical and mental health, relationships, and work (Carers UK, 2015).

There has been a considerable amount of research on the unmet needs of family carers of people with a range of conditions (Cooper et al., 2013; Li & Loke, 2013; Nik Jaafar et al., 2013; Park et al., 2013). Soothill et al. (2001) categorised the unmet needs of family carers in three broad themes: daily life, emotions, and social identity and relationships. On the other hand, comparatively less attention had been given to the experiences and needs of family carers of people nearing the end of life, and recent studies have aimed to explore the needs of such people in depth to address this problem (Aoun et al., 2015b).

Care can take many forms, and in this thesis a broad concept of care will be used, which will include not only practical care, but also other aspects of care, such as emotional support, organisational support, financial support, and so on. Throughout the thesis, the terms *carer* and *caregiver* will be used interchangeably, and care will be defined as the set of activities that provide any kind of meaningful support to a relative who suffers from an advanced, life-threatening disease. Such support can be instrumental, for instance bathing, feeding, or giving medication; emotional, for instance, listening to worries and concerns, either in person or over the telephone or via post/email); information-oriented, including clarifying the treatment or process of the disease, seeking information online on behalf of the patient; financial, for instance contributing to the costs of formal, paid care or equipment; organisational, for example employing someone else to provide the practical care, or coordinating care provided by others; and any other activities that involve any kind of significant support.

2.3. An overview of distance caregiving

Distance caregiving has received some attention in recent decades, with a number of surveys aimed at exploring distance caregiving taking place in the USA and UK (Wagner, 1997; National Alliance for Caregiving, 2004; Carers UK, 2011). Equally, three reviews have summarised evidence on distance

caregiving (Bledsoe et al., 2010; Bevan & Sparks, 2011; Cagle & Munn, 2012). This section will present the following aspects of this phenomenon: proposed definitions of distance caregiving; the characteristics of the caregiver and recipient of care; the care provided by distance caregivers; and the impact of distance caregiving on the carer's employment and finances.

2.3.1. Definitions of distance caregiving

Scientific literature has referred to caring at a distance in a number of ways. Some authors refer to it as distance caregiving, whereas others use the term long-distance caregiving.

A number of studies have used broad definitions, indicating that a distance caregiver is “any individual who provides informal care and/or support to a sick or debilitated friend or family member living far away” (Cagle & Munn, 2012). Another review conceptualised “long distance caregiving as the efforts made by family members to provide for the needs of elderly, often ailing relatives who reside at a location that is sufficiently geographically distant that the caregiver cannot have daily face-to-face contact with the relative” (Bledsoe et al., 2010, p. 295).

Parker et al (2006) provided a comprehensive definition of long-distance caregiving, which emphasised a number of aspects that modulate such experience:

“Anyone (1) who provides informal, unpaid care to a person experiencing some degree of physical, mental, emotional, or economic impairment that limits independence and necessitates assistance; and (2) who experiences caregiving complications because of geographic distances from the recipient, as determined by distance, travel time, travel costs, personal mobility problems, limited transportation, and other related factors that affect the caregiver's access to the care recipient.” (Parker et al., 2006, p. 391)

A doctoral dissertation published in the last decade focused on people who were providing distance caregiving to a parent with cancer, and defined distance caregiving as “the provision of instrumental and emotional support to a person who lives ‘far away’” (Mazanec, 2012, p.2).

While the caregiving aspect of these definitions seems to be reasonably clear in the healthcare literature, the distance variable remains somewhat unclear: there does not seem to be an agreed operational definition. Different studies, reports and policy documents have defined distance in different ways: some have used travelling time to define distance, and others have used mileage.

One of the largest studies on distance caregiving was the Metlife study, published by the USA's National Alliance for Caregiving, and surveyed 1,130 caregivers (2004). They found that the average distance between the distance caregiver and the recipient of care was 450 miles (724 km), with over

7 hours of travel one way. Another study which conducted a secondary analysis of a previous survey examining caregiving reported that the average distance caregiver lived 300 miles (482 km) away from the patient (Koerin & Harrigan, 2003). A previous study which used carers' focus groups to define long-distance adopted the definition of *"living 100 miles or more away from the care recipient"* (Wagner, 1997).

The Metlife study only included distance caregivers who lived *"more than one-hour travel time from the care recipient"*, hence basing the definition on travel time rather than geographical distance (National Alliance for Caregiving, 2004). Similarly, the special report on distance caregiving published by the USA's Alzheimer's Association (Alzheimer's Association, 2013) defined a distance caregiver as someone living 'at least one-hour away' from the patient. Qualitative studies have also used a similar definition of distance. For instance, Roff (2007) defined distance caregiving as *"person who resides at least one hours' drive from a parent"* (p.318).

The recent Carers UK report reported that under a quarter of carers lived over half an hour away, with 5% living two hours away (Carers UK, 2015).

Finally, a few studies have deemed it more appropriate to let the patient/carer dyad decide what *distance* is. Indeed, after publishing a review of communication in long-distance caregiving, Bevan & Sparks (2011) suggested that researchers should define distance *"by allowing the relational partners themselves to determine if they are involved in a long-distance relationship"* (p. 29).

2.3.2. Characteristics of the distance caregiver

Research has consistently indicated that a large proportion of distance caregivers are middle-aged: 60% of the respondents of the Bridging the Gap report in the UK were between 40 and 54 years old (Carers UK, 2011); in the USA this proportion ranged from 58% (National Alliance for Caregiving, 2004) to 76% (Wagner, 1997), and Koerin and Harrigan (2003) reported a mean age of 42 years old.

The general consensus in the caregiving literature is that women seem to become caregivers more commonly than men (Joseph & Hallman, 1998; Payne, 2010a; Carers UK, 2011; Cagle & Munn, 2012). Evidence regarding this issue in distance caregiving is somewhat contradictory: a number of studies have reported similar proportions of males and females providing long distance caregiving, and that the male/female ratio remained similar despite an increase in geographical distance (Wagner, 1997; Koerin & Harrigan, 2003; National Alliance for Caregiving, 2004). These findings challenge the common assumption of female carers being the norm, and may indicate that, while this is often the case in local caregiving, it may not be applicable to distance caregiving (Cagle & Munn, 2012). Two

thirds of respondents in the largest UK-based distance caregiving survey were females (Carers UK, 2011); whereas in the Metlife study (National Alliance for Caregiving, 2004) 58% were men.

The vast majority of the literature on distance caregiving has focused on carers who provide support to an elderly parent. In the UK, 69% of distance caregivers indicated that they were providing care to an elderly parent or parent-in-law (Carers UK, 2011); in the USA, this ranged from 56% (Wagner, 1997) to 76% (Koerin & Harrigan, 2003; National Alliance for Caregiving, 2004). The recipients of care were predominantly female (Wagner, 1997; National Alliance for Caregiving, 2004), with an average age between 78 and 89 (National Alliance for Caregiving, 2004; Cagle & Munn, 2012). Dementia (Alzheimer or other forms) was the most common health problem of the care recipient, who most often lived on their own or with a spouse; the person who helped the distance caregiver was usually a sibling who lived close to the patient (National Alliance for Caregiving, 2004).

2.3.3. Care provided by distance caregivers

Research suggests that, despite the barrier of distance, those who care from a distance provide support in a wide range of areas.

Studies had consistently reported the role of distance caregivers in providing emotional support (Roff et al., 2007; Bevan & Sparks, 2011; Carers UK, 2011). A UK-based survey with 982 distance caregivers reported that 82% provided emotional support (Carers UK, 2011). Distance caregivers have also been found to provide support around organisation and coordination of on-site care arrangements, as well as housework (Bledsoe et al., 2010; Carers UK, 2011), and transport (Bledsoe et al., 2010). Support with legal matters, such as helping with paperwork, financial matters, and obtaining power of attorney, seemed to be a key role of distance caregivers, especially when there were not any on-site carers (Roff et al., 2007; Bledsoe et al., 2010; Carers UK, 2011).

Communication plays a central role in caregiving. Bevan & Sparks produced a review which explored communication in distance caregiving (Bevan & Sparks, 2011). Based on eight studies, the authors concluded a number of recommendations around communication in distance caregiving, highlighting the importance of face-to-face visits, long-term visits, and the crucial role of on-site carers to facilitate distance caregiving (Bevan & Sparks, 2011). This review also described topic avoidance as the process by which the distance caregiver or the recipient of care withheld information from the each other, and enumerated a number of possible motivations, including protecting oneself, the other one or the relationship, or trying to avoid conflict (Bevan & Sparks, 2011).

One study interviewed 22 distance caregivers and focussed on communication between siblings in LDC (Roff et al., 2007). The sample consisted of 10 females and 12 males, living at least one hour

away from an elderly parent (mean distance = 695mi/1,118km). The authors explored issues around coordination of care and how distance caregiving affected communication between siblings, finding that the majority of sibling groups had not established a formal care plan. While some families had experienced different levels of stress due to the strains of care provision, most participants seemed to be happy with the care that the other siblings were providing, and that the need for caregiving together from a distance had improved communication between siblings, compared to that of the period when the parents were healthier (Roff et al., 2007).

2.3.4. Employment and financial impact of distance caregiving

The impact of long-distance caregiving on the caregiver's work situation has also been explored (National Alliance for Caregiving, 2004; Carers UK, 2011). Some studies have placed great importance on the effect of distance caregiving on the caregivers' employment. The Metlife study (2004) reported that 62% of these carers were employed full-time, and 18% part-time. The charity Carers UK commissioned a survey to explore how employees (n=982) and employers (n=52 organisations) managed caring at a distance in the workplace, with the aim of informing policy and improving support to those in this situation (Carers UK, 2011). This report was published under the name 'Bridging the gap', and showed that 43% of carers in this survey indicated that distance caregiving had had a negative impact on their work (Carers UK, 2011). It also provided some insight into the reported needs of distance caregivers in terms of support from their employers. Nearly half of the respondents indicated the need for more information about support for distance caregiving in the workplace; they also expressed the need for awareness of carers' issues in the workplace, and the need for more flexible work hours and patterns was also reported (Carers UK, 2011). Other needs highlighted included having more flexibility in terms of leave arrangements, and having information easily available from home, work or elsewhere (Carers UK, 2011). Finally, while both male and female participants in the Metlife study equally reported having to accommodate their working arrangements to fit distance caregiving, women were more likely to have to miss days off work for distance caregiving, or reduce their working schedule from full-time to part-time (National Alliance for Caregiving, 2004).

The Metlife study (2004) also shed some light on the potential costs of distance caregiving. Participants in this study spent an average of just under \$400 a month in long distance caregiving and travel arrangements. The expenditure increased from \$386 per month for those who lived less than three hours away from the care recipient, to \$674 per month for those who lived more than three hours away. Another USA national telephone survey with 1,000 carers, of which 11% lived one hour away or longer from the care recipient reported that distance caregivers had the highest

annual expense (\$8,728), spending around \$3,000 more than local carers (National Alliance for Caregiving, 2007).

2.4. Palliative care

This section first presents a brief overview of the history and definition of palliative care, before exploring in detail the topic of family carers in palliative care, and the challenges that are specific to them.

2.4.1. A brief introduction to palliative care

Before the advent of modern medicine in the 20th Century, the main goal of medicine was the relief of symptoms. With scientific advances in the early 1900s, such as the discovery of penicillin, the focus of medicine shifted towards a curative intent. However, the alleviation of pain and suffering has always been at the core of medicine, and places of care for the dying have existed for centuries. The first recorded hospices date from the year 400 in Ostia, Rome (Centeno, 1988). Hospices were common during the Middle Ages, where their main function was to welcome pilgrims, who often arrived very ill and sometimes dying (Saunders, 2005). During the second half of the 20th century, the so called modern hospice movement ignited in the UK, where Cicely Saunders founded the St Christopher's Hospice in 1967.

In the late 1990s, the Hastings Centre published a seminal report based on an international collaboration of 14 countries: "The Goals of Medicine: setting new priorities" (Allert et al., 1996). This report concluded on four main goals, two of which are in direct relation to palliative care: the alleviation of pain and suffering due to illness, and the pursuit of a peaceful death (Allert et al., 1996). Following this report, Daniel Callahan, a member of the Hastings Centre, stated that medicine as a whole has two equally important goals: to preserve life, and to provide a peaceful death:

"... since we all die, the preservation of life should not be understood as necessarily a higher ideal than a peaceful death. As ideals, they are of equal value..." (Callahan, 2000, p. 656)

These two publications aimed to balance the emphasis that modern medicine seemed to be putting on ignoring death, by avoiding it at all costs, including the patient's quality of life.

The most widely accepted definition of palliative care was established by the WHO (Sepúlveda et al., 2002). This definition clearly encompasses not only the patient, but also their relatives, and it highlights a holistic approach to the dying person and their treatment:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient’s illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”* (Sepúlveda et al., 2002, p. 94)

This definition implies the need for a multidisciplinary, holistic approach to the provision of care in the last stages of life. With this definition, the focus of palliative care has also shifted from a disease-specific approach to a more inclusive one. This effectively means that palliative care is not only aimed at people with advanced cancer, but that its principles and treatments are applicable to potentially all conditions, insofar as they are life-limiting and not responsive to curative treatment. People with dementia, Motor Neurone Disease (MND) or end-stage cardiorespiratory disease can and should also benefit from supportive and palliative care services. Furthermore, due to the different (and often more complex) trajectories of these diseases, family caregivers may present different needs to those who support a person dying from cancer.

It is estimated that 1.6 million patients die in Europe each year from cancer, and approximately 5.7 million from non-cancer chronic diseases, meaning that, at any given time, over 600,000 people and their families require palliative care support (Radbruch & Payne, 2009). The palliative care movement is nowadays widely spread across Europe (Centeno et al., 2007) and many other countries (Sepúlveda et al., 2002). The UK was recently declared the country with “the best quality of death” in the world (The Economist Intelligence Unit, 2015).

2.4.2. Family carers in palliative care

This section will present the main issues and challenges that are specific to family carers in palliative care: describe the role of family carers in relation to healthcare professionals; examine the needs of family carers in palliative care; and highlight the positive aspects of care, as perceived by the carers.

Individuals who provide care to others without payment are commonly referred to as informal caregivers or family caregivers. This latter term generally includes not only relatives, but also friends and neighbours. While studies have used different definitions of family, the consensus in palliative care is to accept as family the people that the patient considers to be so. The World Health Organisation (WHO) suggested that people who are not relatives, such as friends or neighbours, should also be incorporated into the patient’s family if the patient indicates so (Expert Committee on Cancer Pain Relief and Active Supportive Care, 1990). Authors have supported the WHO’s stance and have proposed definitions of family that include other people outside the traditional family construct, for example, “*the family is who the patient says it is*” (Kissane, 2002). Similarly, Payne & Grande (2013) used the term family carers to refer to “*lay people (family, friends and significant others; hereafter called ‘family carers’) who provide care to patients during advanced illness and through the process of dying*” (p. 579).

The vast majority of research on family members as informal carers has focused largely on caregivers who live near to or in the same household as the person for whom they are caring. While the constraints of distance will inevitably affect the nature of the care provided by carers at a distance, it is important to understand what is generally expected of family caregivers as a background for understanding the expectations and experience of carers at a distance.

When caregiving takes place within the family context, this is influenced by pre-existing family dynamics. Families work as a system, a network of interconnected and interdependent members (Monroe & Oliviere, 2009), and changes to one of the elements of the system (in this case, the patient) affect the system’s dynamics (Kristjanson & Aoun, 2004). This, in turn, affects how the family supports the patient. Often, dynamics vary within a family system, depending on external

stressors and relationships between individuals. For instance, in one same family communication between siblings may be healthy, but at the same time it may be unhealthy between father and mother.

While the term family carer is widely used in clinical practice, research and policy, such people often do not identify themselves as carers, but rather, as family. The caregiver role is one that people often take unbeknownst to them. Some authors have argued that family caregivers learn what to do “by doing it.” Kleinman (Kleinman, 2009) described his own experience as a long-term caregiver for his wife who was suffering from Alzheimer, and argued that family carers “are caregivers because [they] practise caregiving”.

Stajduhar and colleagues (2013) analysed interview data from four qualitative studies involving 156 family caregivers, exploring the processes by which these carers learnt how to provide care to people at the end of life. They identified four main themes: trial and error (this occurred often when there was a (factual or perceived) lack of support from the clinicians), active information seeking (some carers were proactive and tried to find information by reading, calling helplines or talking to others), application from previous knowledge or skills (prior experience of similar situations often provided a sense of confidence), and guidance received by others (this could be either informal, via family and/or friends, or formal, via social workers, medical staff or funeral homes) (Stajduhar et al., 2013).

A recent letter to the BMJ by a junior doctor describing the ambiguous feelings experienced by all the family during the process of death at home by his father illustrated these issues regarding isolation, guilt and resentment in a compelling way: *“We had anticipated the huge impact that Dad’s death would have on our family, [...] We were not similarly prepared, however, for the practical difficulties and emotional challenges of caring for Dad at home”* (Tosh, 2013).

The role of the family in palliative care

Holistic care is at the centre of palliative care, and therefore this discipline aims to provide care not only to the patient, but also to the family. The WHO definition of palliative care is explicit about including families in the care that is provided to the patient: *“palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness”* (Sepúlveda et al., 2002, p. 94). Families in this context are not seen by the clinical team as a separate element from the patient, but are treated as an extension of the patient: as another part of the patient which needs care and attention. However, in many instances the family members also play a role contributing to the care of the patient, although some authors have rightly pointed out that it cannot be assumed that all relatives are carers (Monroe & Oliviere, 2009). They

have a crucial role in providing not only physical, emotional and social care to their dying relative, but also financial and organisational support, and, more importantly, enabling patient choices (Payne & Grande, 2013). Consequently, family members play a somewhat ambiguous role in palliative care (Harding and Higginson 2001), because they are often seen as carers (Monroe & Oliviere, 2009), rather than the recipients of care by the healthcare staff, hence playing a dual role. On the one hand, they are seen by the team as an integral part of the unit of care, and therefore are supported by the team. On the other hand, they also take the role of someone who may help the professionals to care for the patient; in that sense, they may be perceived as part of the caring team (Grande et al., 2009).

Policy documents have also echoed this duality in the role of family carers in palliative care. The End of Life Care Strategy dedicated a chapter to the issue of family carers, recognising their vital contribution to the patient's care, enabling them to die at home if the patient wishes to do so (Department of Health, 2008). This report indicated that carers are *"central to the team that cares for somebody at the end of life and they should be treated as 'co-workers' with the health and social care team"* (p.107), whilst also acknowledging that carers have their own needs, and that these are separate from the patient's needs (Department of Health, 2008). The National Council for Palliative Care (NCPC) held a carers' conference in 2012 and its report similarly emphasised the carers' role, stating that carers simultaneously *"are expert partners in care"* and that they *"need support in every setting"* (National Council for Palliative Care, 2013).

While these needs are analogous to those of family carers providing support to people with other health problems, this issue is particularly apparent in palliative care due to the decline of people near the end of life. This may preclude their care taking place somewhere other than the home, thus having a great impact of the family caregivers. Further, changes in the state of the person receiving care can be rapid and dramatic, which may impact on the carer's needs and role.

The ambiguous role of family carers in palliative care has been examined in the home setting, however it has not been explored in carers who provide care from a distance in palliative care, and their role remains unknown.

What family carers in palliative care do

The needs of patients in palliative care are complex. Consequently, family carers in palliative care provide support in a broad range of areas; some of them share a common ground with family caregiving in other disciplines. These have been summarised by Stajduhar and Cohen (2009) into the following categories: physical care, including helping the patient with personal care, activities of daily living, and wound management; symptom control, which often includes more than one

symptom simultaneously; emotional support to the patient; patient's advocate and proxy decision maker; practical and social support, including household chores and maintaining the patient's pre-existing relationships; and coordination of care, which includes pre-death and post-death planning (Stajduhar & Cohen, 2009). Other authors have categorised end of life family caring into six spheres: emotional and psychological; familial and social; financial, including direct financial support and also organisation of financial support by others; information and communication, including matters around the illness and other issues, such as legal matters and paperwork; physical and personal care; and spiritual or existential care (Payne & Morbey, 2013).

A recent publication drew on the results from a post-bereavement national survey of 1,504 people who had been caring for a person who died from cancer in the UK (Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017). The survey focused on the last three months of life of the patient, and reported how carers spent a mean of almost 10 hours per day providing care, and this care comprised emotional support, social support, shopping, cleaning, home maintenance and food and drink preparation. This survey also looked at carer's expenditure on caregiving: three quarters of respondents indicated out-of-pocket expenditure, of which the most frequent was travelling expenses, with a median cost of £100 over the last three months of the patient's life (Rowland et al., 2017).

[The needs of family carers in palliative care](#)

Family caregivers in palliative care are a particularly vulnerable population and present a number of specific needs. Many studies have explored the needs of families in palliative care.

Carers' needs are highly individual. However, authors have summarised the needs of family caregivers in palliative care in different ways. Stajduhar and Cohen (2009) identified three areas of carers' needs, closely related to their caring role: physical needs (sleep, nutrition, safety), psychosocial needs (preventing social isolation, psychological support, privacy), cognitive needs (having breaks from the emotional burden of caring by being able to access respite care), financial needs (transport, home adaptations), and formal/informal support (effective communication, acknowledging the carer's suffering) (Stajduhar & Cohen, 2009). Another study identified three main areas of family carers' needs: managing symptoms, being able to identify the signs of imminent death, and learning what their role involves and what resources are available to them (Hudson, 2013).

One study asked family caregivers of people with advanced cancer about the most difficult challenges that they were facing (Hudson, 2004). Themes identified included the carers' own ill health, the lack of support from healthcare professionals, the additional stress caused by family

issues, the lack of time for themselves, the patient's deterioration, and their lack of skills in symptom management. Another qualitative study explored the unmet needs of 32 family caregivers of people with metastatic cancer and an expected survival of less than 12 months; these caregivers were either active (n=17) or bereaved (n=15) (Mangan et al., 2003). The authors identified unmet needs around five themes: relating to medical care, quality of life and burden, help received/needed from others, positive aspects of caregiving, and a “miscellaneous” category, where they grouped unsolicited themes, such as informational needs from sources other than the healthcare team, or the impact of the disease on the family or their job (Mangan et al., 2003).

A recent systematic review summarised the self-reported unmet needs of patients and carers who were receiving home-based palliative care (Ventura et al., 2013). This review is particularly relevant for two reasons. First, it highlighted that there is not a standard definition of unmet needs in palliative care, and it provided a working one: unmet needs “*refer to the self-perceived needs of patients and carers that require professional attention in addition to what is already provided*” (Ventura et al., 2013, p. 392). Second, it included only studies with participants who were providing care at the time when the studies took place, rather than doing so retrospectively (i.e. bereaved relatives or medical records). Nine studies were identified, of which only four reported unmet needs of carers’ alone; the rest also included the patients’ needs. Unmet needs around the following areas were most commonly reported: communication with doctors and nurses; spirituality; psychosocial issues; practical needs (e.g. access, transport); information (carers seemed to be especially concerned about what to do at the time of death, and about their role as caregivers); respite care; isolation (not only psychological, but also physical isolation); and loss of autonomy.

Issues around information are often central when carers are asked about their needs in palliative care and a recent literature review (Convey et al., 2008) stressed its importance. First, it highlighted how not only family caregivers felt that clinicians needed to improve information communication, but also believed that it was essential to adapt the timing of the communication to the carer's individual characteristics, and to improve the integration of care between services. Second, it provided an exhaustive checklist with information needs on different areas, including disease information, equipment and accessibility, and befriending services (Convey et al., 2008).

Considerable attention has been given to the needs of family carers in palliative care in recent years (Grande et al., 2009; Payne, 2010a, 2010b), including the development of a Carer Support Needs Assessment Tool (CSNAT) aimed at carers who provide end of life care in the home (Ewing et al., 2013a). One of the studies by this group consisted of qualitative interviews with 60 informal carers who were providing care at home to a relative who was receiving palliative care (80% to a patient

with cancer) in the UK (Grande et al., 2004). This study aimed to identify the areas of support that were most important to family carers in this setting, and for each category positive and negative examples were found. Following content analysis, eight themes were identified: being able to access healthcare staff; enlisting help from other agencies, such as GPs, district nurses or hospice involvement; provision of equipment and supplies, for instance medicines or equipment for personal care; attitudes or behaviour during interactions, both from GPs and from district nurses; relationships with healthcare professionals; support for the carer, especially when staff checked to see how the caregiver was doing; information about the patient's illness, especially being given the desired amount of information; symptom control (Grande, Farquhar, Barclay, & Todd, 2004).

A number of interventions have aimed to address the unmet needs of family carers in palliative care. Many programmes have aimed to support caregivers in palliative care, including family therapy, burden and depression reduction, social care, problem solving, group educational programmes and one-to-one psycho-educational programmes (Payne & Hudson, 2008). A systematic review (Harding & Higginson, 2003) summarised and appraised the effectiveness of interventions targeted at caregivers. Interventions were of the following types: home care, respite care, social networks and activities, one-to-one interventions, and group work. The same study highlighted how psychological and informational needs are the most urgent, followed by practical and financial needs (Harding & Higginson, 2003).

A Cochrane review summarised evidence from 11 randomised controlled trials (RCTs) (total n=1836) that assessed the effects of interventions designed to support informal caregivers (Candy et al., 2011). None of those interventions provided practical support. Rather, they involved facilitating coping skills, financial advice or emotional support. Overall, findings indicated that these types of interventions may help improve the psychological wellbeing of family carers (Candy et al., 2011).

Despite the considerable work around the needs of family carers in palliative care, the needs of those who provide such care from a distance remain largely unexplored.

Positive aspects of family caregiving in palliative care

The last months, weeks and days of the life of a person are often treasured by their relatives. Some research has been conducted exploring the positive aspects of caregiving in palliative care. Mangan and colleagues (Mangan et al., 2003) prompted participants to talk about positive aspects of caregiving for a relative near the end of life in a study using focus groups. The main themes revolved to feeling respected by the healthcare staff, and the sense of closeness it prompted in the family. In a study exploring the meaning of support as narrated by 20 spouses of older people near the end of life, Stolz (2006) identified two positive aspects in caring: "experiencing togetherness with others",

by means of being confident that they were surrounded by a network of formal and informal carers that were ready to help if needed; and “sensing togetherness with oneself”, by realising that they were able to face the challenges posed to them by the act of caregiving. Hudson (2004) interviewed 47 home-based palliative care family caregivers and asked them to explain any positive aspects that they had found in their role as caregivers. Sixty percent of the participants were able to find positive elements of their role as carers, such as feeling closer to the patient or learning about personal strength.

2.5. Literature review: Distance caregiving in palliative care

The previous section has provided an overview of distance caregiving in general, without limiting it to palliative care. This section will present a literature review examining the scientific literature on distance caregiving specifically in palliative care.

2.5.1. Methods

This literature review searched peer-reviewed journals and grey literature. The following databases were searched using the Ovid platform, using a combination of terms around “caring”, “caregiving”, “distance” and “palliative care” (the full search strategy can be found in Appendix 2.1):

- Embase
- Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)
- PsycINFO

Publications were included if they reported results from primary research exploring caring at a distance, with samples composed of people with an incurable, life-limiting disease, regardless of the illness (i.e. including non-cancer populations) and the clinical setting. Included studies could be published in peer-reviewed journals, or be grey literature such as PhD dissertations. Publications were excluded if they focused on local caregiving, or if they were secondary data analysis, for instance literature reviews.

This search retrieved 65 records. Following the screening of abstracts and titles based on the inclusion and exclusion criteria indicated above, 63 records were excluded. Only two publications were related to distance caregiving in palliative care (Smith et al., 2009; Mazanec et al., 2011). In addition, grey literature and reference lists were searched. This resulted in the identification of two PhD theses that explored the issue of distance caregiving in advanced cancer (Cagle, 2008; Mazanec, 2009). Hence, a total of four publications from three different studies were included in this literature review (see Appendix 2.2 for the characteristics of the studies).

2.5.2. What do we know about distance caregiving in palliative care?

Smith et al. (2009) presented a single-case study of a young Guatemalan female with fatal leukaemia in the USA's healthcare system, and lightly touched on the subject of geographical distance in undocumented migrant patients with advanced cancer. While this is an interesting case study raising many issues that members of the Latino community may face in the USA, it did not explore distance caregiving in any depth. Nonetheless, this study reported that, in Latino populations, patients' vulnerability may be heightened when their families have remained in the patient's country of origin, and hence are unable to visit or provide care locally (Smith et al., 2009). One of the main strengths of this paper is that the case was reviewed in a holistic manner, with the intervention of a chaplain, medical student, and interpreters, all of which helped the palliative care team provide support to the patient and her family. This approach resulted in a rich paper that examined different dimensions of palliative care, including spiritual and psychosocial care. Further, the article focused on the cultural and language barriers, bringing a unique standpoint to palliative care. It provided guidelines on how to improve communication with the patient when language is a barrier, as well as recommendations for working with interpreters when communicating about end of life care (Smith et al., 2009). However, this article based its conclusions and recommendations on a single case, and thus may not be applicable to different circumstances, for instance other cultures, family situations or healthcare settings. The main limitation in regards to the purpose of this doctoral dissertation is that the paper only briefly mentions the issue of distance, as it was not its aim to explore the issue. Nonetheless, Smith et al. (2009) highlight the importance of family support in palliative care even if at a distance, and the detrimental effect of the lack of it.

In the last decade, two doctoral theses have looked at distance caregivers in advanced cancer (Cagle, 2008; Mazanec, 2009).

Cagle explored the social and psychological needs of informal caregivers of people with advanced cancer receiving hospice care (Cagle, 2008). The study compared survey results from co-residing and proximate (living less than one hour away) caregivers (n=106) and distance caregivers, which were defined as living more than one hour away from the patient (n=25 completed the pre-death survey, and n=8 completed the post-death survey). Long-distance caregivers in this study lived an average of 559mi (899km) and 6.3 hours away from the recipient of care. Their mean age was 58 years old, and 68% (n=17) were female (Cagle, 2008). This PhD looked at differences in social support and psychological adjustments over time and between the different groups of carers (long distance, local

and co-residing), and found no significant differences between distance groups or within groups (comparing before and after death). Although interesting, the quantitative results from this study must be taken with caution, as the findings are based on a small sample. The author also analysed the free text comments that survey respondents added at the end of the survey, looking at comments from 56 surveys completed pre-death, and comments from 26 surveys completed post-death, regardless of the distance. Eight pre-death themes were identified: preparedness/preparation; expressions of gratitude; anger/criticism of care; the role of friends; needs and sacrifices; information and education; faith and spirituality; and sense of obligation/giving back. The four post-death themes reported by this study were: information and education; religion and spirituality; gratitude; and grief and loss (Cagle, 2008). When looking specifically at the comments from long-distance caregivers, distance was found to be a barrier, and respondents reported frustration at having to rely on the on-site carers, as well as a sense of worry and lack of information (Cagle, 2008). The author recognised a number of limitations in his thesis, such as the biased sample, small sample size, methodological challenges and concerns about instrument validity (Cagle, 2008). However a number of additional limitations were found. First, the qualitative findings from this study were based on the comments that survey respondents wrote in the open ended question at the end of the questionnaire: *"Please use the space below to make any additional comments about how you could have been better prepared/supported during the care of your loved one."* (Cagle, 2008, p.121). Eighty-two comments were analysed, of which only a minority were around distance caregiving. Second, the sample in this study included only patients with cancer, so its findings may not be applicable to people with non-cancer conditions and their carers. Third, in this study 'distance caregiving' was pre-defined (distance caregivers were those who lived more than one hour away from the patient) (Cagle, 2008), rather than allowing participants to identify themselves as being at a distance, thus potentially missing information from carers who lived nearer to the patient but still felt the care they were able to provide was limited by the distance. Although with limitations, this study provided relevant information about distance caregiving in end of life care, a topic that had been previously neglected.

Finally, Mazanec published a number of papers about distance caregiving to a parent with cancer (Mazanec, 2009; Mazanec et al., 2011; Mazanec, 2012) reporting the findings of her PhD thesis (Mazanec, 2009). This analysed the experiences of adult children who were providing care to a parent with advanced cancer, and compared survey results from local caregivers (n=40) and distance caregivers (n=40) (Mazanec, 2009). Distance caregivers were found to be significantly more likely to be married, have siblings and have higher education degrees than local caregivers, and only seven of the 40 distance caregivers identified themselves as the primary caregiver (Mazanec, 2009). The

study also measured stress predictors and psychological well-being outcomes in 40 local caregivers and 40 distance caregivers. This study included long-distance caregivers who lived at least 100 miles (160 km) away from the patient. Although the results were not significant, this study reported that four variables were associated with the caregiver's psychological well-being: cancer stage, caregiver age, caregiver gender and distance, and four further variables were linked to the caregivers' reaction (defined as a construct that combined caregiving benefits and burden): caregiver race, status as primary caregiver, having other dependents, and the distance (Mazanec, 2009). The study also reported higher levels of anxiety, distress and mood disturbance in distance caregivers, when compared to local caregivers (Mazanec, 2009).

In addition to the survey, this study also conducted telephone interviews with a subsample of distance caregivers (N=14), asking them three questions about their experience and what advice they would provide to nurses and other family carers in their situation (Mazanec, 2009, 2011). This part of the study identified five overarching themes. The first theme was Benefit/Burden of Distance Caregiving, and revolved around the positive and negative aspects of such role. Negative feelings around distance, travelling at short notice and guilt were found in relation to burden. Positive aspects were in relation to not having to witness the reality of cancer every day, and also being able to have a deeper connection and feeling that distance caregiving had brought them together to their parent. The second theme was Struggling With Uncertainty, and most participants in Mazanec's study talked about the uncertainty around the illness, its outcome and the treatment, about when to travel to see the patient, and about "what was actually happening at home" in terms of how the patient was feeling physically and emotionally. Mazanec's third theme was Direct Action through Information Seeking, as a way of coping with this sense of uncertainty. The fourth theme was Protecting, and analysed the mutual instinct to protect each other, whereby the parents (patients in this study) tried to 'protect' their distance caregivers (children) by hiding information, and the children would do the same trying to "*put on a strong façade*" by providing their parents with positive testimonies of survivorship and hope. The final theme from this study was Staying Connected. This theme was present in all interviews, and revolved around staying connected to the patient, keeping in touch with the healthcare staff, and in some cases was also around religious faith, and communicating with other distance caregivers for mutual support (Mazanec, 2009, 2011).

One of the main strengths of this study was the use of mixed methods, which generated rich, multifaceted data that addressed a range of aspects of the experience of distance caregiving. On the other hand, the study presented a number of limitations. It used a convenience small sample size: there were 40 distance caregivers in the survey, of which only 14 were interviewed by telephone. The sample was, similarly to Cagle (2008), largely white and highly educated, and hence the findings

may not apply to populations with other sociodemographic profiles. The survey in this study used a questionnaire that included items that were only applicable to *local* caregivers (Mazanec, 2009). Finally, this study only looked at caregivers whose relative had advanced cancer, and as such its findings are limited to this group. Nonetheless, the two publications by Mazanec (2009, 2011) were a valuable source of information about distance caregiving in palliative care.

A common limitation to the three studies (four publications) included in this literature review is that all of them were USA-based, and as such their approach to palliative care may not be applicable to different cultural settings or healthcare systems.

2.6. Chapter summary

This chapter has examined the topic of family caregiving from different perspectives. First, definitions and conceptual frameworks about caring were presented. The second section explored the phenomenon of distance caregiving in general, without limiting it to palliative care. The third section presented palliative care as a context for family caregiving, detailing the aspects that are specific to palliative care, including the issue of family carers having an ambiguous role. Finally, the fourth section presented the methods and results of a literature review on distance caregiving in palliative care.

Family caregivers in palliative care carry out a myriad of tasks for the people that they provide care to, including: physical care, not only in regards to hygiene and personal care, but also providing support with medication and symptom control; home care, including daily chores and home modifications and adaptations; social support, for example, preserving and maintaining family and social relationships; coordination of care provided by others and providing information; legal and financial care; and emotional and spiritual care. The majority of these caregiving tasks overlap with those of carers in other settings, however the issues that are specific to palliative care shapes the experience of providing care and the impact this has on the caregiver.

In regards to caregiver needs, this chapter has looked at the specific needs of caregivers in palliative care, and showed how needs around information and communication (including being given the appropriate amount of information), spiritual needs and symptom management are particularly relevant in this setting. Other needs were similar to those experienced by carers in other settings, such as burden, psychosocial needs, help needed from others, practical help, and the carer's own ill health.

This chapter has shown how distance caregiving in palliative care is a complex phenomenon that has received very little attention from researchers and policy makers. This sub-group of family carers

remain a largely invisible population. Very little is known about distance caregivers in palliative care, and a number of questions remain unanswered: who are distance caregivers in palliative care (their relationship to the patient, their sociodemographic characteristics, how far do they live from the patient)? Does geographical distance change the relationship with the patient, from the point of view of the caregiver? What care do they provide to the patient, and is that different to the care provided by local caregivers? And, more importantly, what resources and support do distance caregivers in palliative care need to enable them to provide the care they would like to provide to their loved one?

This doctorate will aim to address these gaps in research by exploring in depth how distance shapes the nature of family caregiving in palliative care, the characteristics and experience of such carers, and their needs.

Chapter 3: Ehealth in palliative care

3.1. Chapter overview

This chapter focuses on one of the three core elements of this doctorate: ehealth. First, the chapter will introduce the paradigm of ehealth, providing definitions and briefly describing the societal changes that have made this phenomenon possible. The next section will describe the status quo of ehealth in the context of palliative care. This will be followed by a section reporting the methods and results of a literature review exploring ehealth interventions involving family carers in palliative care.

3.2. The paradigm of ehealth

During the last third of the 20th century and the early years of the 21st century, breakthrough developments in technology have substantially transformed society: we now live in what has been called the Information Society (Mansell, 2009). The key feature of the Information Society is the use of technology for two main purposes: gathering, storing, processing and analysing information, for instance, medical records or research databases; communicating regardless of the distance, for example, using email or text messaging (Mansell, 2009). These technologies have been called the ICT, and are central to the Information Society, in the same way that the industrial society was based around analogue machines:

“In recorded history there have perhaps been three pulses of change powerful enough to alter [humankind] in basic ways. The introduction of agriculture... The Industrial Revolution... [and] the revolution in information processing technology of the computer” (H. A. Simon, quoted in Masuda, 1980, p. 3)

The advent of the Information Society has greatly affected all spheres of human life, including commerce, government, culture, learning and, to a lesser extent, healthcare (Anderson, 2007; Kruse et al., 2016). For a number of years now, stakeholders in healthcare have been using ICT in many ways, including but not limited to: provision and exchange of health information (e.g. healthcare research articles); storing medical information (e.g. medical health records); healthcare training (e.g. e-learning for healthcare professionals); or to provide healthcare interventions (e.g. counselling online). A new term that encompasses all these was coined at the turn of the century: ehealth (Eysenbach, 2001). The World Health Organisation defined ehealth as:

“The use of information and communication technologies (ICT) for health. Examples include treating patients, conducting research, educating the health workforce, tracking diseases and monitoring public health.” (World Health Organisation, 2015)

The terms *ehealth* or *use of ICT in healthcare* will be used throughout this thesis to refer to this phenomenon.

Early definitions of ehealth emphasised the empowerment of *“consumers and patients - by making the knowledge bases of medicine and personal electronic records accessible to consumers over the Internet, e-health opens new avenues for patient-centred medicine, and enables evidence-based patient choice”* (Eysenbach, 2001, p. 1). The emergence of ehealth has been intertwined with a paradigm shift in the healthcare arena. Until a few decades ago, the biomedical model had dominated the medical landscape (Engel, 1977; Suls & Rothman, 2004). In this model, there was a very clear hierarchy of power: patients typically did not have much knowledge about medicine or healthcare, and accepted the views of the medical establishment. During the last few decades a new healthcare model has emerged: the biopsychosocial model (Suls & Rothman, 2004). In this model, patients actively seek information about their health problem(s) and take a central role in the decision making process: the collaboration between healthcare professionals and patients is key.

The current person-centred care agenda in the NHS and the increasing role of Patient and Public Involvement (PPI) in the planning and implementation of healthcare in the UK (Patients and Information Directorate, 2013) exemplify this changing emphasis. On the other hand, this paradigm shift has brought new challenges, including tensions between stakeholders (Ferguson & Frydman, 2004). A recent example of this may be the controversy surrounding the anti-vaccination movement, where parents decide not to immunise their children based on their own research, and against the policy recommendations (Greenberg, 2015; The Guardian, 2015). These examples highlight the significant changes that the field of healthcare is experiencing. This paradigm shift has facilitated the advent of ehealth, and, simultaneously, ICTs are enhancing this change by providing a space (the internet) where people can seek, create, and share health information with peers and professionals.

The recent WHO report ‘Global diffusion of eHealth: Making universal health coverage achievable’ (World Health Organization, 2016) reported on the findings from its third global survey on ehealth, which confirmed the continuous growth of the use of ICT for healthcare. This report indicated that 47% of member countries have now implemented national electronic health records systems, and that over three quarters of countries have legislation in place to protect the privacy of personal information (World Health Organization, 2016).

3.2.1. Social media in healthcare

Social media refers to users' activity on a range of online platforms that allow them to create, share and modify information. This might be in the shape of text (e.g. blogs), pictures (e.g. Instagram) or videos (e.g. YouTube). One of the most comprehensive definitions of social media was provided by Kaplan & Haenlein (2010):

"Social Media is a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0., and that allow the creation and exchange of User Generated Content." (Kaplan & Haenlein, 2010, p. 61)

The majority of healthcare providers worldwide, either in the public or private sector, use social media as a way to engage with and provide information to their users: the largest global survey reported that healthcare organisations in nearly 80% of countries use social media for public health (World Health Organization, 2016). In the UK, the NHS and other healthcare providers routinely use Short Messaging Services (SMS) reminders about appointments (Car et al., 2008). Equally, it is not uncommon for rigorously designed studies nowadays to include social media as a strategy to recruit participants, or to disseminate their results.

3.2.2. The Web 2.0

Social media is a very recent phenomenon, which started in the early years of the 21st century and has fully developed during the 2010s. Its advent is not an isolated occurrence: it has taken place within the paradigm of the Web 2.0.

The term *Web 2.0* was coined in 2001 by technology publisher and thinker Tim O'Reilly, together with his colleague Dale Dougherty, in order to denote the differences between the first period of the internet and the more recent times. One of the defining features of the internet in its early years was that the information was provided in a unidirectional manner: only companies and organisations created content (web sites full of information), and lay people were consumers of this information, but were not able to participate or to create it. In this aspect, the internet was similar to television: content was created and delivered by a minority of people with a specific set of skills and resources, and was consumed by the rest. As the Web evolved, this changed and users became proactive, initially by writing web logs, sharing their experiences or opinions. These online publications, later known as blogs, were the first form of social media. As blogs proliferated, other social media platforms started to surface, such as Facebook, which became mainstream following its

creation in 2004. The creation of social media platforms meant that literally anyone with an internet connection could create content for the Web. This is the core of the Web 2.0: the internet is not only populated by information created by a few people, but also by information created by its users. Other forms of social media include online forums, collaborative project such as Wikipedia, video communities (for instance, YouTube), virtual game and social worlds (Kaplan & Haenlein, 2010). Social networking sites such as Facebook or Twitter, however, remain its most popular forms. The Web 2.0 has been defined in the following way:

"Web 2.0 is the network as platform, spanning all connected devices; Web 2.0 applications are those that make the most of the intrinsic advantages of that platform: delivering software as a continually-updated service that gets better the more people use it, consuming and remixing data from multiple sources, including individual users, while providing their own data and services in a form that allows remixing by others, creating network effects through an "architecture of participation," and going beyond the page metaphor of Web 1.0 to deliver rich user experiences." (O'Reilly, 2005)

3.2.3. Barriers to the adoption of ehealth

Despite the apparent success of ehealth, barriers to the adoption of the use of ICT for healthcare have been identified. The results from the global WHO survey reported that the main barriers for the adoption of ICT were: lack of funding to develop and implement such programmes; lack of infrastructure (both in terms of technology equipment and network coverage and connectivity); competing priorities in their health systems; and the lack of regulations and legislation (World Health Organization, 2016). The findings from this survey echo those from a recent literature review that examined the evidence around the same topic (Kruse et al., 2016). This review identified 33 different barriers as reported by previous publications in seven areas of the world, and organised them into three categories. The first group were barriers for organisations, and these included obstacles such as cost, legal, security, and privacy issues, effectiveness and workflow, and outdated equipment. The second category of barriers were those identified by patients, and included, amongst others, age, education and computer literacy levels, and bandwidth. The last group of barrier related to staff and programmers, including but not limited to items such as resistance to change, technically-challenged staff, licensing, and poor design (Kruse et al., 2016).

In regards to barriers to the use of electronic healthcare records, a previous study explored the barriers perceived by physicians, and identified the following themes: concerns over customisation (for instance, not being able to tailor the system so that it would be fit for purpose), cost issues,

logistics/regulatory issues, including the lack of national standards, return on investment issues (for instance, being unsure about the benefits of such investment), integration issues, concerns about adopting a new technology, reimbursement issues, “herd mentality” and social influence (including the lack of organisational support), and a need for control (Vishwanath & Scamurra, 2007).

Consistent with these perceived barriers, ethical guidelines from professional bodies are limited, which may pose a barrier to researchers and practitioners (Casañas i Comabella & Wanat, 2014).

3.3. The use of ehealth in palliative care

The first part of this section will examine the use of ehealth in palliative care. This will be followed by a literature review of the different ehealth initiatives that have been reported to date for family carers in palliative care: the objective of this review was to identify publications that reported the use of ICT by this population.

A number of ehealth interventions have been tested in palliative care, and there is a growing interest in the topic (Kidd et al., 2010; Johnston, 2011; Capurro et al., 2014). Furthermore, recent publications on distance caregivers of elderly people and people with advanced cancer have highlighted the potential of the use of technology to improve outcomes in this particular population (Mickus & Luz, 2002; Benefield & Beck, 2007; Demiris et al., 2008; Cagle & Munn, 2012; Mazanec, 2012; Alzheimer's Association, 2013). Recent publications reflect the increasing use of social media by palliative care professionals (Nwosu, 2012; Nicholson, 2013; Taubert et al., 2014; Nwosu, 2015).

A systematic review assessed publications that analysed the effectiveness of interventions using ICT in palliative care, whether with patients, caregivers or healthcare providers (Capurro et al., 2014). Seventeen studies were included in this review, which reported the use of various methods (for instance, web sites and telephone calls) by healthcare staff, patients and family caregivers. The interventions were around the following areas: education, telephone support, software and hardware to monitor patients' symptoms, and telephone or online questionnaire administration (Capurro et al., 2014). The review reported unequal levels of efficacy, with three studies having showed improved contact with caregivers. The studies included ranged from observational, non-controlled and quasi-experimental designs, and none of them were randomised controlled trials (RCT) (Capurro et al., 2014).

3.3.1. Literature review

Despite this growing interest in ehealth, the paucity of original research on distance caregivers precluded a literature review focussing on ehealth initiatives for this specific population, as this

would have resulted in a very small number of results. In light of this, the literature review aimed to summarise the effects of the use of ehealth in interventions for *any type* of family carers in palliative care, thus not limiting it to distance caregivers. Therefore, the research question that guided this literature review was:

- What are the effects of ehealth interventions aimed at family carers in palliative care, regardless of the distance from the patient?

Ehealth in this literature review was defined as indicated in Chapter 1 and in section 3.2 of the present chapter: the use of ICT for health.

3.3.1.1. Methods

The following databases were searched using the Ovid multi-database platform:

- AMED (Allied and Complementary Medicine)
- Embase
- Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)
- PsycINFO
- CINAHL
- PROSPERO

The search terms used comprised a combination of the terms 'carers', 'ehealth', 'ICT', 'Information and Communication Technology' and 'palliative care'. The search strategy used for this literature review is detailed in Appendix 3.1.

Publications were included in this review if they:

- Reported original research about the use of ICT by family carers in the provision of palliative or end of life care, regardless of the diagnostic.
- Included family carers in the sample.
- Used qualitative or quantitative or mixed methods.
- Were written in English language.

Publications were excluded from this review if they:

- Were secondary research.
- Did not report the use of ICT by family carers, or did not report the findings for family carers separately from other participants (for example, patients or healthcare staff).
- Did not report any outcomes about family carers, even if they had been involved in the intervention. For example, papers were excluded if they described the use of an ehealth

intervention where patients and caregivers had been involved but only reported the findings in regards to the patients.

- Were research protocols, or publications limited to the description of an intervention without reporting any findings.
- Focused on a telephone-only intervention, without including any other technologies.

3.3.1.2. Results from the literature review

A total of 431 publications were identified through the multi-database search, and a further five were found by examining reading lists. No records were found in the PROSPERO database. These 436 were then screened by title and abstract based on the inclusion and exclusion criteria, and 398 papers were excluded. Thus, the full text of 38 publications was examined, and this resulted in the exclusion of a further 26 papers. Hence, the final number of articles included in this review was 12 papers, pertaining to six different studies. The flowchart in Appendix 3.3 illustrates this process. A table summarising the papers' characteristics, including sample, setting, intervention, design, findings, and quality rating can be found in Appendix 3.4.

Of the 12 articles included, eight were from the USA (Coleman et al., 2005; Demiris et al., 2007; Demiris et al., 2011; Demiris et al., 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010; Gustafson et al., 2013; DuBenske et al., 2014), two were from Australia (Bensink et al., 2009; Bradford et al., 2012), one from Canada (Stern et al., 2012), and one from Sweden (Lind et al., 2008). Five publications stemmed from the same study (Demiris et al., 2007; Demiris et al., 2011; Demiris et al., 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010), two articles reported findings from one study (Bensink et al., 2009; Bradford et al., 2012), and a further two papers were from another study (Gustafson et al., 2013; DuBenske et al., 2014). The remaining publications included in the review reported results from independent studies (Lind & Karlsson, 2004; Coleman et al., 2005; Stern et al., 2012).

The study designs in these studies were diverse, and included two case studies (Lind et al., 2008; Parker Oliver & Demiris, 2010), three pilot studies (Demiris et al., 2007; Bensink et al., 2009; Bradford et al., 2012), one randomised trial (Gustafson et al., 2013; DuBenske et al., 2014), one prospective cohort study (Bradford et al., 2012), one qualitative study (Demiris et al., 2013), and three mixed methods studies (Coleman et al., 2005; Parker Oliver et al., 2010; Stern et al., 2012). One publication did not specify the design used (Demiris et al., 2011). All the interventions were aimed at people who could access these services from home; that is, a patient/family carer who could remotely access these services while being at home. The quality of the publications included

was variable and generally low, both for the quantitative studies and the qualitative ones (see Appendix 3.4).

Most of the studies explored the use of videoconferencing systems that allowed the caregivers (and often the patients) to interact in some way with healthcare staff. In two studies, videoconferencing gave carers access to scheduled specialist consultations with palliative care consultants (Bensink et al., 2009; Bradford et al., 2012). Other publications examined how videophones enabled carers to join palliative care team meetings via videophone (Demiris et al., 2007; Demiris et al., 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010), to consult specialist nurses available 24 hours a day (Stern et al., 2012), or access a brief problem-solving therapeutic intervention (Demiris et al., 2011). Two studies looked at other types of interventions, namely a pain treatment follow-up using a specially designed pen diary (Lind et al., 2008), and a website especially targeted at people with non-small cell lung cancer (NSCLC) (Gustafson et al., 2013; DuBenske et al., 2014).

Nine publications reported the use of videoconferences to enable family carers to participate in team meetings or have video consultations. Bensink et al. (2009) presented the results of an acceptability study that explored the use of a videotelephone system to support families who received paediatric oncology-related palliative care in Australia. This team had initially been set up to conduct an RCT, however they were unable to recruit any families into the study despite two consecutive attempts, the first one in 2006, and the second one between late 2006 and 2007, because most eligible families declined to take part in both attempts (Bensink et al., 2009). Following this, the team made a decision to carry out an acceptability study exploring whether providing videotelephone support to families in this palliative care setting was acceptable. While the two failed RCTs faced serious challenges in terms of recruitment, the acceptability study obtained a high participation rate, as 11 out of the 12 families approached consented to take part (Bensink et al., 2009). From the initial 11 families recruited, only seven received the intervention, alongside standard care. The other four families dropped out from the study: three due to the death of the patient, and one family moved to another geographical area to pursue a second opinion. The mean distance between the families receiving the intervention and the hospital was 430 km (Bensink et al., 2009). Twenty-five videotelephone consultations took place with nurses, with a median call length of 20 minutes (Bensink et al., 2009). Most of the calls included the mother and/or the father of the paediatric patient, and covered a range of symptoms (for example, pain, constipation or neurological changes), practical issues (for example, medication advice or home equipment), and emotional support to the carer, the patient or the sibling of the patient (Bensink et al., 2009). While the article concluded that videotelephone support was acceptable in this setting, the reasons for this were not stated and the paper was overall of low quality (see section 3.3.1.3.).

The same research group conducted another pilot study, assessing the quality of life of caregivers in 14 families in the same setting (Bradford et al., 2012). This study initially intended to recruit a sample of 30 participants, however the project had to be stopped prematurely due to attrition, and thus the study obtained consent from 14 caregivers, most of which were the mothers of the child receiving palliative care (Bradford et al., 2012). The children in this study were receiving care for neurological, oncology, metabolic, genetic or cardiac diseases, and their ages ranged from birth to 18 years old; the ages of the parents were between 25 to 55 years old (Bradford et al., 2012). Two of the children died before the caregiver was allocated to the study arm, and hence only six caregivers were included in each arm (total participants in the study: n=12). The study administered the 16-item Quality of Life in Life Threatening Illness-Family (QOLLI-F) instrument (Cohen et al., 2006) to measure quality of life in participants every two weeks for a total of 10 weeks. However, by the end of the study complete data could only be obtained from four participants in the control arm (standard care, originally n=6) and two in the intervention arm (telecare group, originally n=6). The study reported that there were no differences in quality of life between the intervention group and the control group (Bradford et al., 2012). The authors discussed the challenges around recruitment in palliative care studies, and emphasised in their conclusions the importance of carefully planning research projects in this field in order to minimise participant burden (Bradford et al., 2012).

Demiris and colleagues published several articles exploring different aspects of the use of a videoconference system by caregivers in hospice settings (Demiris et al., 2007; Demiris et al., 2011; Demiris et al., 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010).

This research group conducted a pilot study exploring the feasibility of the use of videophones by senior caregivers from two USA-based hospices, and published selected results in different articles (Demiris et al., 2007, Demiris et al., 2013). The first publication (Demiris et al., 2007) reported the findings from a pilot study exploring the feasibility of videophones as a tool for service delivery in two hospices (one rural, one urban). The study recruited 12 family caregivers, most of which were females and either spouses or adult children of an elderly patient. All patients but one had cancer (Demiris et al., 2007). After consent was obtained, the research team installed bespoke videophones in the homes of the senior caregivers, and they were instructed to use it as they would normally use a regular telephone to communicate with the hospice (Demiris et al., 2007). The caregiver's anxiety and quality of life were measured every other week using validated measures, and by the end of the study it was found that the anxiety scores had decreased significantly, but that there were no changes in quality of life scores. Although the article reported that the caregivers felt that being able to "see" the team increased their level of security, the authors recognised in the discussion that the

changes in anxiety could not be attributed solely to the videophone communication, and that further research was needed to explore this type of intervention (Demiris et al., 2007).

In a second publication, the same research team examined the feasibility of using a videophone that enabled hospice patients and their live-in family caregivers to join the team meetings remotely (Parker Oliver et al., 2010). This pilot study took place in two rural hospices in the USA and used a two-stage mixed methods design. During stage one of the study, patients and caregivers received standard care; this was considered the historical comparison group. During stage two, videotelephones that allowed a remote connection with the team were installed in the patients' homes; this was the intervention group (Parker Oliver et al., 2010). The study hypothesis was that, by enabling caregivers to take part in the team meetings, their perception of pain medication and management, as well as their quality of life, would improve. To this effect, the Caregiver Perceptions of Pain Medicine Questionnaire (CPMQ) (Letizia et al., 2004) was administered to caregivers throughout the pilot, together with other quality of life and communication anxiety questionnaires.

A total of 75 caregivers were recruited for the study, of which 41 received standard care (historical control group), and 32 attended staff meetings remotely in addition to receiving standard care (intervention group) (Parker Oliver et al., 2010). In both groups, the majority of caregivers were females, of white ethnicity, and an adult child or a spouse providing care to the patient at home. The authors indicated that attrition was a challenge during the study, and only 15 caregivers in the intervention arm (total n=32) had completed the questionnaires by the end of the intervention. Despite not finding any significant differences between groups, the authors concluded that the intervention was feasible, as caregivers were able to use the technology for the purposes of the study (Parker Oliver et al., 2010).

This article was followed by a further publication by Demiris and colleagues (2013), which explored the views of participants on the intervention (being able to attend hospice team meetings remotely using a videotelephone). Data for this study were obtained conducting 19 telephone interviews with family caregivers at the end of the pilot (Demiris et al., 2013). Overall, participants felt that participating in the team meetings via videotelephone was a positive experience, and found it useful to be able to communicate with the team as a whole and take part in the meetings (Demiris et al., 2013). Participants were asked about their impressions on the quality of the web-based videoconferencing system. The issues expressed by caregivers around technical challenges were categorised in four groups: 1) audio delay, and how this affected communication during the meeting, 2) difficulty to hear all the people in the meeting through the videotelephone, 3) problems with the overall video quality, such as unclear images or the video "freezing up", and 4) ease of use of the

videotelephone (Demiris et al., 2013). The study concluded that, despite the technical challenges encountered, telehealth tools such as the videoconference system trialled provided a valuable opportunity for caregivers to join team meetings, and for hospice staff to obtain the caregivers' information about the patient (Demiris et al., 2013).

A feasibility study was conducted by the same research team, investigating the feasibility of using videophones to deliver problem-solving therapy (PST) to 42 family caregivers who had a relative in a hospice (Demiris et al., 2011). The PST was delivered by a therapist over a bespoke videophone system, and validated instruments were used to assess participants' levels of anxiety, quality of life and problem-solving behaviour (Demiris et al., 2011). While only the reduction in anxiety was statistically significant after the intervention, the majority of participants and therapists expressed high satisfaction with the videophone therapy (Demiris et al., 2011).

Parker Oliver and Demiris (2010) published a Brief Communication where they reported findings from a case comparison study that compared the delivery of the PST in two caregivers: one of them received the PST face-to-face in their home, and the other one received it via a bespoke videotelephone system. Both participants were female, 64 years old, and had a parent receiving care in the hospice (one parent had cardiovascular disease, and the other parent had dementia and cardiovascular disease) (Parker Oliver & Demiris, 2010). The intervention consisted of an initial session to explain the intervention and obtain consent, three sessions of PST (face-to-face in one case, and remotely in the other one), and a final visit to interview the participants about their experience (Parker Oliver & Demiris, 2010). The authors reported that both participants were very satisfied with the intervention, and concluded that the study demonstrated the feasibility of telehealth for the delivery of this type of therapies (Parker Oliver & Demiris, 2010). In regards to technical issues, one of the three videoconferences had to revert to regular telephone call, as the video connection could not be established, and the authors highlighted the importance of having an alternative mode of delivery when technological problems arise, so that the care can continue regardless (Parker Oliver & Demiris, 2010).

On the same topic, Stern and colleagues (2012) presented a mixed methods case study exploring how palliative cancer patients and their family carers perceived home telehealth. The intervention consisted of providing patients and their caregivers with a videotelephone that was used to communicate with "tele-nurses" (nurses with expertise in palliative care). The service was available 24-hours, and video calls could be initiated by families or nurses alike (Stern et al., 2012). Participants were also provided equipment at home that allowed nurses to remotely monitor the patient's blood pressure, blood oxygen levels, and heart, lung and abdominal sounds. The authors

interviewed 12 family carers (five as patient-caregiver dyads, and seven bereaved family caregivers), and combined these data with observations and nurses' notes. Over half of the caregivers in the study were spouses, and they were all providing care to a patient with cancer (Stern et al., 2012). The mean length of the intervention was 3.5 months, ranging from two weeks to six months. Of a total of 255 contacts, 88 (35%) were video contacts, 22 video contacts included remote monitoring, and 8 of those remote monitoring contacts had technical problems. Finally, only 35 (14%) contacts were initiated by the caregiver (Stern et al., 2012). The study reported findings from three sources (patients, caregivers and nurses) simultaneously, making it difficult to distinguish whether themes were identified by interviewing/observing participants, or from the nurses' notes. Nevertheless, ten of the 17 participants interviewed in the study were caregivers. Two main themes were identified following latent content analysis: Enhanced access to care, and Usability of the home telehealth system. Caregivers reflected on the lack of service integration, as face-to-face visits from community nurses took place in parallel as part of standard care outside the study, causing confusion to some participants. All but one caregiver felt that being able to see the nurse via the videotelephone was beneficial, although almost half of the families felt that the timing of the intervention was not ideal, and that the telehealth system would have been more valuable if it had been introduced earlier in the disease trajectory (Stern et al., 2012). In terms of the usability of the system, families, patients and nurses reported that, despite the equipment being easy to use, there were some technical problems (Stern et al., 2012).

The remaining four publications reported on different uses of ICT, namely web-based support systems and the use of a digital pen for pain assessment.

Two articles reported the results from a randomised control trial which evaluated the use of a tailor-made online web support service by 285 advanced non-small cell lung cancer (NSCLC) targeted at both patients and caregivers (Gustafson et al., 2013; DuBenske et al., 2014). Patient and caregiver dyads were recruited at four different cancer centre hospitals in the USA. Both arms in this study received standard care, and the study supplied all participants with a laptop and reimbursed the cost of the internet connection during the study; at the end of the study, all caregivers could keep the computers (Gustafson et al., 2013; DuBenske et al., 2014). Study participants were randomised into two arms: people in the control arm (n=141) received training on using the internet and a list of recommended websites about lung cancer, and those in the intervention arm (n=144) were given access to the 'Comprehensive Health Enhancement Support System' (CHESS), which was a web-based communication, coaching and information tool for caregivers (Gustafson et al., 2013; DuBenske et al., 2014). The CHESS website was created with the aims of: providing information about lung cancer, caregiving and bereavement; serving as a communication channel for patients,

caregivers and clinicians; acting as a coach by providing feedback based on the data generated by users; and providing tools to improve the caregiving experience (Gustafson et al., 2013; DuBenske et al., 2014). In both groups, the vast majority of caregivers were women, over 94% lived in the same household as the patient, and around half of them were highly educated (Gustafson et al., 2013; DuBenske et al., 2014).

The hypothesis in the first publication (Gustafson et al., 2013) was that patients in the CHESS arm (intervention arm) would have less symptom distress than those using the internet. The study also looked at the survival rates in both arms. Participants (caregivers and patients) completed postal surveys every two months, up to 24 months, although the analyses were only run on the data from the first eight months of the study (Gustafson et al., 2013; DuBenske et al., 2014). Following study withdrawals, 124 dyads received the intervention (CHESS), while 122 dyads used the internet. At two months, only 59 dyads completed the symptom assessment in the CHESS group, and 65 did so in the internet arm; at eight months, the number of dyads completing the assessment was 43 and 42, respectively (Gustafson et al., 2013). The only significant difference found between groups was in relation to patient physical symptom distress, which caregivers in CHESS arm reported as lower at four and six months (but not at two and eight months). In regards to the use of CHESS, 73% of caregivers used it at least once, 51.6% of all caregivers used CHESS five times or more, the median length of time caregivers spent on CHESS was 103 minutes, and the median number of pages viewed by caregivers was 147 (Gustafson et al., 2013).

The analysis performed by Gustafson and colleagues (2013) also looked at survival, comparing the median survival of three groups: those patients in patient-caregiver dyads who used CHESS (n=62), those in the internet arm (n=122), and those who had not used CHESS despite being in the CHESS arm (also n=62). Although patients in the CHESS arm who did use the website lived for a longer period of time, a 2-year survival analysis indicated that survival rates did not differ between groups (Gustafson et al., 2013).

In a second publication (DuBenske et al., 2014), the same team reported the effects of this intervention on caregiver's mood, burden and disruptiveness. Disruptiveness was defined as *"the degree to which caregiving tasks interfere with the caregiver's regular daily routine of life activities"* (DuBenske et al., 2014, p. 1256). The authors' hypothesis was that, at six months, caregivers in the CHESS group would present lower levels of burden, disruptiveness and negative mood than those in the internet group (DuBenske et al., 2014). Both burden and disruptiveness in this study were measured using the Caregiver Quality of Life – Cancer Scale (CQOLC) (Weitzner et al., 1999), and mood was assessed with the Short Version Profile of Mood States (SV-POMS) (DiLorenzo et al.,

1999). Data for this analysis was based on the surveys completed by caregivers at six months: in the internet arm, 49 caregivers completed the CQOLC disruptiveness sub-scale, 51 also completed the CQOLC burden sub-scale, and 52 completed the SV-POMS; in the CHES arms, the figures were 44, 44, and 45 caregivers respectively (DuBenske et al., 2014). On comparison of the two groups, the CHES arm presented significantly lower burden and negative mood, but no significant differences were found in disruptiveness. The authors noted in their discussion that the lack of significant changes in disruptiveness may reflect measurement factors, as they found floor effects in this sub-scale, which may indicate that the instrument was not adequate for the study (DuBenske et al., 2014).

Lind and colleagues (2008) conducted a qualitative study looking at how patients and caregivers used a digital pen for pain assessment. The system allowed patients, or their family carers, to rate the patient's pain levels and send them online to the healthcare team instantly, while remaining at home. Twelve patients were recruited for the study, and interviews were also conducted with four spouses, and later analysed using qualitative content analysis. While most of the results from the study focussed on the patients' experience, the authors also reported some findings in regards to the caregivers. All spouses taking part in the interviews were women, and the age range was 56 to 73 years (Lind et al., 2008). Although technical problems seemed to be minor, the study reported that when they did occur, partners helped the patient and tried to solve the issue. It was also found that they played a role reminding the patient to carry out their pain assessment and send the data to the healthcare team through the device. Finally, the article reported that the use of the digital pen system increased patients' and spouses' contact with the healthcare team, which in turn lead to "a sense of increased security and calmness" (Lind et al., 2008, p. 134).

Finally, one study examined 600 posts from a USA-based online chat room (social media) for patients with pancreatic cancer and their families (Coleman et al., 2005). The website was created purposely for this population by a team of nurses and physicians, and contained information on different aspects of pancreatic cancer such as treatment options, research, type of tumours, genetics, clinician roles, appointments and bibliography, a frequently asked questions (FAQ) section, and an online chat room where patients and caregivers could post, read and reply to messages (Coleman et al., 2005). The study aimed to compare the changes in the chat room posts before and after the addition of the FAQ section, and to this end the authors analysed 300 posts before this module was added, and 300 posts after its addition (Coleman et al., 2005). While not specifically focussing on palliative care, the extremely poor prognosis of pancreatic cancer (Vincent et al., 2011) made this article relevant to this review. This study reported that almost half of the messages were posted by family

members, of which the largest proportion were the daughter of the patient (31%), and the main change found after the addition of the FAQ section was a 3-fold decrease of questions about fatigue in the posts (Coleman et al., 2005). The article examined the content of the posts and categorised the findings in three main categories: information seeking, giving or both; support seeking, giving or both; and reporting either the status or the death of the patient that used to participate in the chat room (Coleman et al., 2005). In regards to information, the paper reported that requests around palliative care and hospice care and end of life symptoms were not uncommon, and that the deterioration of the patient prompted posts by the caregiver which often showed the caregiver's lack of information about disease progression (Coleman et al., 2005).

3.3.1.3. Quality appraisal of the included publications

The quality of the publications included in the review was assessed using different instruments, depending on the study design:

- RCT: CONSORT statement's tool for assessing the quality of RCTs (Moher et al., 2001).
- Pilot studies: adaptation of the CONSORT checklist that has been specifically modified to evaluate pilot studies (Thabane et al., 2010).
- Qualitative design: the Critical Appraisal Skills Programme (CASP) qualitative checklist (2014).

Samples of all three instruments can be found in Appendix 3.2. The quality of the publications was variable. However, since the results from the review were limited, publications were not excluded from the review because of poor quality.

The CONSORT checklist (Moher et al., 2001) was used to assess the quality of the article by Gustafson and colleagues (2013). This article was found to be of medium-high quality, as it reported specifically on the majority of the items in the checklist; the article indeed stated that the authors used the CONSORT guidance for the analysis (Gustafson et al., 2013). However, the publication did not provide enough details about each arm to allow replication, and did not indicate how the sample size was calculated; instead, it recruited all eligible patients who were diagnosed with NSCLC. Furthermore, there was little information about the randomisation sequence and who assigned the participants to interventions, potential harm was not discussed, and the article did not provide the trial registration number or links to the study protocol. Despite these, the authors complied with most of the CONSORT items.

The other publication about this RCT by this research group (DuBenske et al., 2014) was also assessed with the RCT CONSORT checklist (Moher et al, 2001) and was found to be of high quality. The article provided information about the majority of the required items in the CONSORT checklist,

giving very detailed information about the theoretical underpinnings of the intervention, randomisation methods used, participant flow in the study including attrition, and thoroughly discussed its limitations.

The CASP list of ten questions (2014) was used to appraise the quality of the publication by Lind and colleagues (2008), which was found to be of medium-high quality. While overall the authors addressed many of the items required by this checklist, the publication did not discuss the limitations of the study, provide enough information about potential ethical issues, or detail how the themes were identified (Lind et al., 2008).

The study assessing the use of telehealth in the home in palliative care with mixed methods (Stern et al., 2012) was evaluated with the CASP tool as it placed its focus on the qualitative element of the research. This article was found to be of medium-low quality. While the authors clearly stated the aims of the research, the findings, the methodology used and how the data were collected, there was little information about the recruitment strategy, potential ethical issues, and the process of data analysis. Further, the authors did not provide details about how they had integrated both strands of research methods (qualitative and quantitative), or what was the rationale to use such study design.

Bensink et al. (2009) explored the acceptability of videotelephone in palliative care in a paediatric oncology setting in Australia. The quality of this study was assessed using the adapted CONSORT checklist (Thabane et al., 2010), and the publication was found to be of low quality. Despite providing a good overview of the failed RCTs prior to the acceptability study, and stating the objectives, inclusion criteria, participants, settings, and intervention clearly, there were some important omissions. First, the article failed to describe the outcomes for the acceptability study clearly. Second, the baseline data were minimal, and did not describe any of the participants in the study (parents and nurses). Third, it did not provide the criteria for assessing the success of the study (why the intervention was found to be acceptable), other than the nurses being able to recruit families into the study. Fourth, the publication did not discuss the generalisability of the findings. Further, the article did not discuss any limitations or potential bias.

Another publication from the same group was included in this review: a pilot study which explored the impact of videoconferencing in the quality of life of a cohort of 14 families who received the same intervention, although in this case the children had a range of diseases: neurological, oncology, metabolic, genetic and cardiac (Bradford et al., 2012). The quality of this study was appraised using the CONSORT checklist adapted to evaluate pilot studies (Thabane et al., 2010), and it was found to be of medium quality. While many of the necessary elements were reported appropriately, a

number were missing, such as: accurate description of the intervention, study objectives, feasibility outcomes, criteria for the success of the intervention being piloted, study limitations and generalisability, thus precluding it from obtaining a higher quality rating.

Demiris and colleagues published a number of publications stemming from the same intervention, exploring caregivers' use of a videoconference system (Demiris et al., 2007; Demiris et al., 2011; Demiris et al., 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010).

The first publication by this group was a pilot study evaluating the feasibility of videophones as a tool for service delivery in two different hospices (Demiris et al., 2007). Following appraisal with the adapted CONSORT checklist (Thabane et al., 2012), the quality of this study was found to be of medium-high quality, as it reported correctly a number of necessary elements, such as: the scientific background for the study; the setting and eligibility of participants; the characteristics of the intervention; the overall hypothesis and objectives; how the sample size was determined; the ethical aspects and consent; and reflected on the limitations and how the findings should be interpreted. However, the article failed to state the objectives and outcomes that were specific to the feasibility, the flow of participants through each stage of the study, the methods of statistical analysis, and only provided minimal information about the caregivers' baseline characteristics.

The quality of the second publication by this research team (Parker Oliver et al., 2010) was found to be low when appraised using the adapted CONSORT checklist (Thabane et al., 2012). While the study was presented as a pilot testing the feasibility of the intervention, the authors provided little information about the feasibility outcomes, criteria, specific feasibility objectives. Further, the interpretation of the results in regards to feasibility was poor and did not state which aspects of the intervention were being assessed for this purpose. The publication did however reflect on its limitations, such as the small sample size, and the attrition challenges.

A further publication on the same study by Demiris and colleagues (2013) evaluated the views of family caregivers about the use of videotelephones to join hospice team meetings remotely. The quality of this publication was assessed with the CASP checklist (CASP, 2014). While the article clearly stated its aims and findings, used the appropriate methodology, and collected the data in a way that addressed the research issues, the overall quality was found to be medium, because it failed to consider ethical issues, which were even more relevant as the study was part of an ongoing trial, and did not consider the relationship between participants and researcher. Further, the information provided about the methods of data analysis lacked the necessary detail.

Demiris and colleagues also conducted a study where 42 hospice caregivers used videoconferencing to access three sessions of PST (Demiris et al., 2011). The quality of this study was also appraised using the adapted CONSORT checklist (Thabane et al., 2012) and found to be low for a number of reasons. The authors stated that the aim of the study was to explore the feasibility of the intervention, but failed to indicate the study design, the study hypothesis, or the feasibility objectives and outcomes; the baseline information about the sample was minimal; there was no information about the protocol or the flow of the participants through each stage of the project; the only information about the study setting was “hospice caregivers”; and little detail was provided about the characteristics of the intervention.

Two researchers from this team reported the findings from a case comparison study in a separate publication, where they compared the delivery of PST face-to-face versus via videotelephone (Parker Oliver & Demiris, 2010). The quality of this paper was found to be low when appraised with the CASP checklist (CASP, 2014). While the aims or the research and the findings were clear, the article did not provide any details about the methods used, discuss potential ethical issues, consider the relationship between the participants and the researchers, and there was no information on the recruitment strategy or why those two particular participants had been selected. Moreover, the paper did not address any limitations, and it was unclear whether the research design was appropriate to address two of the aims of the research (assessing feasibility and exploring the experience of participants receiving the intervention online). Finally, differences and similarities between the experiences of the two participants were not discussed; instead, it was reported that the two participants were equally satisfied with the intervention.

The publication by Coleman and colleagues (2005) was found to be of medium-high quality when assessed with the CASP checklist (2014). The article clearly stated the aims of the research, provided detailed information about ethical issues, methods of data collection and analysis, and provided a clear statement of findings. However, the study did not consider the relationship between the researchers and participants, or the impact that the posts may have on the researchers, there was not enough information about the data analysis used, and the value of this piece of research was unclear.

3.4. Summary of this chapter

This chapter introduced the last of the three core elements of this doctorate: ehealth. First, it provided a detailed overview of the paradigm that facilitated the advent of ehealth, and the changes that this has brought to healthcare and the delivery of services. It showed how, despite a number of barriers hindering its development, many countries have adopted the use of ehealth. Second, the

chapter presented the methods and findings from a literature review that examined the provision of ehealth services for family caregivers in palliative care.

The review summarised the results reported by 12 publications in regards to the use and experiences of ehealth by family carers in palliative care.

It is worth noting once again that no original research was found on how *distance* caregivers use ehealth in palliative care. Instead, all the studies identified examined the use of ehealth by family carers who were in the same household as the patient. Further, the quality of the publications included in the review was found to be variable, with only one paper being of high quality, and a third of them being found of low quality.

Based on the results of this review, a number of gaps in this area of research have been identified. All studies except two looked at the role of videoconferencing systems in enabling caregivers to participate in meetings or consultations with palliative care staff, and showed that family caregivers value *seeing*, rather than just *hearing* the clinical team and healthcare staff. This highlighted a crucial gap in this area of research. On one hand, all these studies used their own devices: videophones designed specifically for healthcare use. None of these studies looked at what patients and carers were *already* using, and how they were using them. This essential aspect of ehealth in palliative care remains unexplored.

There is a lack of studies looking specifically at the experiences of caregivers using ehealth. The studies identified by this literature review were small-scale feasibility studies, and hence large-scale studies that assess the effectiveness of ehealth interventions for family caregivers in palliative care are needed.

Further, none of the studies identified aimed to evaluate the use of ehealth by distance caregivers in palliative care. Once again, this sub-group of family carers remains unseen.

Chapter 4: Methodology and methods

4.1. Chapter overview

This chapter provides a rationale for the research methodology selected for this doctorate, and describes the research methods used. First, the study design employed, mixed methods, will be described, the underpinnings of this research paradigm will be provided, and its implementation for this study will be detailed. After that, the chapter will describe the population of interest, and the inclusion and exclusion criteria used to select participants in the study. This will be followed by the description of how potential research participants were identified and recruited for the study. A section will follow describing the methods of data collection, including the development and testing of the questionnaire used in the survey, and the development and testing of the interview topic guide. Finally, the last section will explain in detail the methods of data analysis employed in this study: the analysis of the data from the questionnaires using descriptive statistics, the analysis of the data from the interviews using Framework Analysis, and how qualitative and quantitative data were integrated.

As stated in Chapter 1, this study aimed to explore the experiences of people who provide care from a distance to a relative who is near the end of life (hence, within the field of palliative care), and to look at how they use ICT in their role as distance caregivers, with a view to provide the understanding needed to provide them with appropriate support.

The overarching research questions were:

1. How does being at a distance shape the nature of family caregiving in palliative care?
2. What are the characteristics and experiences of distance caregivers in palliative care?
3. What are the needs of distance caregivers in palliative care?
4. How do distance caregivers in palliative care use ICT in their role as carers?

4.2. Study design

The choice of methods for any research project must be guided by the research question and objectives. The set of research questions for this doctoral study were complex, and could best be answered by using mixed methods.

Elements of the research questions around the sociodemographic characteristics of distance caregivers in palliative care, how far they lived from the patient, and what kind of ICT they used to provide care from a distance were suited to quantitative methods. The qualitative aspects related to understanding in more detail how these people provided care, and what their experience was, were better answered using qualitative methods. Hence, mixed methods were employed in this study to provide rich and multifaceted answers to a set of complex research questions. The type of mixed methods used in this study was a convergent mixed methods design.

This section will outline the theoretical underpinnings of mixed methods research; detail the specific mixed methods approach that were used in this study; and explain why a convergent parallel mixed methods approach was chosen as the most appropriate to address the study's research questions.

4.2.1. Mixed methods research

Mixed methods research is a relatively recently established research paradigm and consists of the combination of both quantitative and qualitative research methods in order to provide comprehensive answers to research questions that would could not be appropriately addressed by using a single approach (either qualitative or quantitative). Hence, one of the main features of mixed methods is to overcome the inherent limitations of using quantitative or qualitative methods exclusively.

Creswell and Plano Clark (2010, page 5) defined mixed methods as:

"[Mixed methods research] focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone."

Mixed methods emerged as a research approach in the late seventies (Creswell & Plano Clark, 2010), and has been characterised not only as a pragmatic effort to overcome the limitations of a binary research paradigm (i.e. perceiving quantitative and qualitative paradigms as mutually exclusive), but also an alternative approach to answer complex research questions. By using an approach that is not limited *only* to numbers (quantitative) or *only* words/concepts (qualitative), mixed methods enables

researchers to explore phenomena in a different way. Mixed methods is not the mere sum of quantitative and qualitative research, but it is a different approach altogether: it aims to generate a whole that is greater than the parts.

Greene and colleagues (1989) coined mixed methods as a *complementary* approach, where “different methods are used [...] to enhance the interpretability of assessments of a single phenomenon - for example, via broader content coverage or alternate levels of analysis” (Greene et al., 1989, p. 257). This feature made mixed methods a very attractive approach for the research questions of this doctorate, since it enabled the researcher to look at a phenomenon (in this case, distance caregivers in palliative care and their use of ICT to provide care) from different angles in order to achieve a more detailed, deeper understanding that takes into account all its dimensions.

There are a number of different approaches or ways to combine quantitative and qualitative methods in mixed methods research, and several typologies have been proposed. Creswell and Plano Clark (2010) classified mixed methods into the following categories:

- *Convergent parallel design*: both quantitative and qualitative methods are used independently and simultaneously; findings from both methods are merged at the end of the study.
- *Explanatory sequential design*: quantitative methods are used initially to collect and analyse data, and these are then followed up by qualitative methods.
- *Exploratory sequential design*: similar to the above, but the sequence of methods is inverted: qualitative methods are used first to collect and analyse data, and then quantitative methods are used building on the results from the first stage.
- *Embedded design*: quantitative and qualitative methods are used in combination, but one of the methods is prioritised, while the other one is nested. This may be done before, during or after the main method is used.
- *Transformative design*: mixed methods are used in the context of a theoretical framework, and its use is strongly guided by that.
- *Multiphase design*: both quantitative and qualitative methods are used at different stages of the same study.

A mixed methods design was selected for this study in order to provide a more comprehensive and multifaceted understanding of the research problem, as stated by Klassen and colleagues (2012):

The use of mixed methods is most suitable when a quantitative or qualitative approach, by itself, is inadequate to develop multiple perspectives and a complete understanding about a research

problem or question. Researchers may seek to view problems from multiple perspectives to enhance and enrich the meaning of a singular perspective. (Klassen et al., 2012, p. 378)

In this doctorate, the use of qualitative interviews complemented survey findings by providing a deeper understanding of the complexities of distance caregiving in palliative care. Both methods contributed different perspectives on the same topic, thus resulting in a better understanding of the complex phenomenon of distance caregiver.

4.2.2. Mixed methods research in palliative care

This section will provide a brief overview of how mixed methods have previously been used in palliative and end of life care research.

Mixed methods as a methodological approach has recently received some attention from palliative care experts (Farquhar et al., 2013). The Medical Research Council's (MRC) *Guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care* (Evans et al., 2013) recommended considering mixed methods as an approach to research in end of life care, and the MORECare Statement on good research practice recommending research designs extending *"beyond randomised trials and encompassing mixed methods"* (Higginson et al., 2013, p. 1). Farquhar and colleagues (Farquhar, Ewing, & Booth, 2011) advocated for the use of mixed methods in the development and evaluation of complex interventions in palliative care. Indeed, the nature of palliative care means that most interventions are complex, and therefore mixed methods as an approach is particularly suited: *"insights gained from quantitative and qualitative approaches complement each other to provide more in-depth understanding"* (Farquhar et al., 2011, p. 749).

Waldrop (2007) used a mixed methods design to study caregivers' grief in a cohort of 30 people who were interviewed at two different points in time (before the death of their relative, and one year after that). In this study, qualitative and quantitative methods had equal weight and were used in parallel: two validated PROMs were used in conjunction to the interviews, which were semi-structured (Waldrop, 2007). A further example of mixed methods research in palliative care may be found in a recent Portuguese study which explored burnout in 118 palliative care nurses from nine different palliative care teams (Pereira, Fonseca, & Carvalho, 2012). This study put more weight on the qualitative methods, namely in-depth, semi-structured interviews with at least nine nurses, and observation of 240 hours of team meetings; it also used a validated PROM to assess the nurses' levels of burnout, and 73 nurses completed the questionnaire. Both sets of data (qualitative and quantitative) were used as complementary aspects of the study to provide a comprehensive picture of nurses' burnout (Pereira et al., 2012).

Finally, another study followed the MRC complex interventions framework and used a mixed methods approach in order to develop an intervention addressing advance care needs of people with advanced dementia and their carers (Sampson et al., 2008). The authors used a sequential design and hence comprised two distinctive phases (first a qualitative study, then an exploratory trial) and used a mixture of PROMs, interviews with patient-carer dyads and palliative care assessments.

4.2.3. Rationale for choosing a convergent parallel mixed methods design

A number of factors contributed to the decision to use mixed methods in this study. Obtaining findings from both quantitative and qualitative methods provided a way to overcome the weaknesses of each approach with the strengths of the other one, thus providing a multifaceted understanding of the research problem. The combination of both quantitative and qualitative methods to collect and analyse data enabled the researcher to explore different aspects of the research questions in a complementary way, and broaden the conclusions covering different dimensions of the same research problem.

Creswell and Plano (2010) proposed other factors when considering this approach, including: maximising data collection in a limited time, both qualitative and quantitative data having equal value to address the research questions, and the researcher/supervisory team having both quantitative and qualitative research skills; these factors matched the circumstances of this doctoral study. While pragmatism is deeply embedded in the epistemology of mixed methods research and has been seen “*as the philosophical partner for mixed methods research*” (Johnson & Onwuegbuzie, 2004, p. 16), this approach to research is also rigorous and systematic. A study reported how pragmatism, together with comprehensiveness, is often one of the deciding arguments for researchers to opt for mixed methods (O’Cathain et al., 2007).

4.2.4. How mixed methods were used in this study

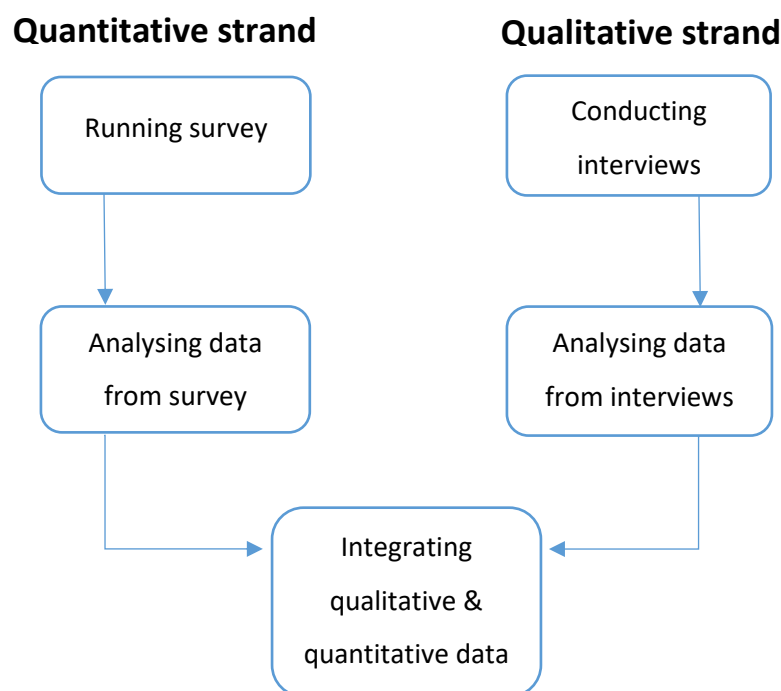
The study was initially set up as an embedded mixed methods design, whereby a secondary, smaller dataset (qualitative) is embedded into a larger dataset (quantitative) (Creswell & Plano Clark, 2011). A survey would be the principal method of data collection, and qualitative interviews would be the embedded method, hence providing an additional view to results from the survey. It was envisaged that the survey would achieve a much larger number of respondents, hence obtaining statistically significant results. However, the final sample size for the survey was smaller than expected, despite

substantial recruitment efforts. Thus, the qualitative part of the study became the stronger element, precluding it from being the embedded design initially conceived. Therefore, the mixed methods approach used was convergent, whereby both methods of data collection and analysis were treated separately and the results are integrated during the discussion.

The study design (see Figure 4.1) used followed three steps, as advised by Creswell and Plano Clark (2010):

- 1) Gathered survey and interview data (quantitative and qualitative data respectively) concurrently, in parallel with each other.
- 2) Analysed the data gathered using each method independently. Later sections of this chapter will detail the analysis process.
- 3) Integrated the results from the survey and the findings from the interviews, focusing on how they complemented each other. Both data sets were given the same weight: neither was treated as more important than the other, because they both answered different aspects of the research questions.

Figure 4.1. How a convergent mixed methods design was used in this PhD



4.3. Population of interest

This section explains in detail who the population of interest were for this study, and the inclusion and exclusion criteria set for research participants.

4.3.1. Target population

The target population for this study were distance caregivers in palliative care. For the purposes of this study, distance caregivers were defined as people who had experience of providing any kind of significant care from a distance to a relative who was near the end of life. This could be a current situation (current carers) or a past event (former carers). Former carers were invited to participate in the study if the patient had died at least six months ago (in order to avoid contacting people at a very vulnerable time), and within the last three years (to ensure adequate recall).

After careful consideration, it was decided not to specify what “distance” meant in this study. The reason for this was to include people who self-identified as living at a distance from the patient, regardless of the definitions outlined in Chapter 2 of this thesis.

4.3.2. Inclusion and exclusion criteria

Inclusion criteria

Potential participants were invited to participate in the study if they were:

- Male or female, aged 18 or above.

And were either:

- A relative who had past or present experience of providing any kind of support to a person near the end of life.

Or

- Identified by the patient as a relative who was involved in caring, albeit at a distance. Such distance limited how often they could visit because they lived far away.

Exclusion criteria

Potential participants were excluded from the study if they were:

- Unable to understand or speak English language.
- Unable to read or write.

4.4. Identification and recruitment of participants

Participants were recruited first for the survey. At the end of the questionnaire, people were asked to provide their contact details if they were interested in being interviewed. Details are provided in section 4.4.5. “Recruitment for the interviews.”

Potential participants were contacted in two ways:

- Through the patients. The University’s Faculty Research Ethics Committee (FREC) advised that, in the instances where potential participants were approached through a hospice or trust, recruitment was done via the patient, rather than sending a questionnaire directly to the participant (that is, the carer) without asking for permission first. A number of sites were used as Participant Identification Centres (PICs), as defined by the NHS Health Research Authority (HRA).
- Through social media. Adverts about the study were posted in different social media outlets.

Both recruitment strategies are described in detail in this section.

4.4.1. Ethics and Research Governance

Prior to the start of data collection, ethics approval was sought and obtained from a number of appropriate sources:

- Oxford Brookes University’s FREC (letter of approval is shown in Appendix 4.1).
- NHS Research Ethics Service (NRES) (letter of approval shown in Appendix 4.2).
- Trusts’ Research and Development (R&D) departments.
- In the case of independent hospices, ethics approval was obtained via their own ethics committees, after having obtained NRES approval.

Prior to applying to NRES, an application was submitted for a proportionate review (Proportionate Review Service) in September 2013. NRES’ proportionate reviews are advised for studies that present no material ethical issues, for example questionnaire studies or interviews on non-sensitive issues. The rationale behind that first application was that this study targeted relatives of patients, instead of patients, and that it was questionnaire based. However, the Proportionate Review Service deemed that the study needed to go through a full NRES review, and a second application was submitted, this time to the full NRES committee.

Gaining ethics approval in participating PICs

Following University and NRES approval, ethics applications for each of the PICs were put forward. All PICs (see Table 4.1) had their own ethics and governance systems in place. Three of the hospices were part of the same charity, and hence only one ethics application was needed for those. For all the other PICs, individual applications were made and subsequently approved. In one case (Hospice 2, see Table 4.1) a small amendment was suggested in order to reiterate to participants that their participation in the survey was completely voluntary.

Once ethics approval was granted, staff at the PICs started recruiting participants for the study. Overall, the process of gaining access to participants took a considerable amount of time, as governance systems varied considerably depending on the PIC and approvals were granted at different stages.

4.4.2. Recruitment of research participants through PICs

A total of seven hospices and one hospital unit in South East England were approached and agreed to identify potential participants for the study (see Table 4.1).

Table 4.1: Characteristics of PICs

PIC	Services (specialist palliative care)
Hospice 1	Inpatient beds; day hospice; community services.
Hospice 2	Respite care & end of life care for children and young adults.
Hospice 3	Inpatient beds; day hospice; community services; bereavement support team; lymphoedema clinic.
Hospice 4	Inpatient beds; day hospice; community services; lymphoedema clinic; lymphoedema clinic.
Hospice 5	Inpatient beds; day hospice; community services; bereavement care.
Hospice 6	Inpatient beds; day hospice; community services; bereavement care.
Hospice 7	Inpatient beds; day hospice; community services.
Non-hospices	Services
Motor Neuron Disease Centre	Multidisciplinary team; tests & diagnostics; coordination of care.

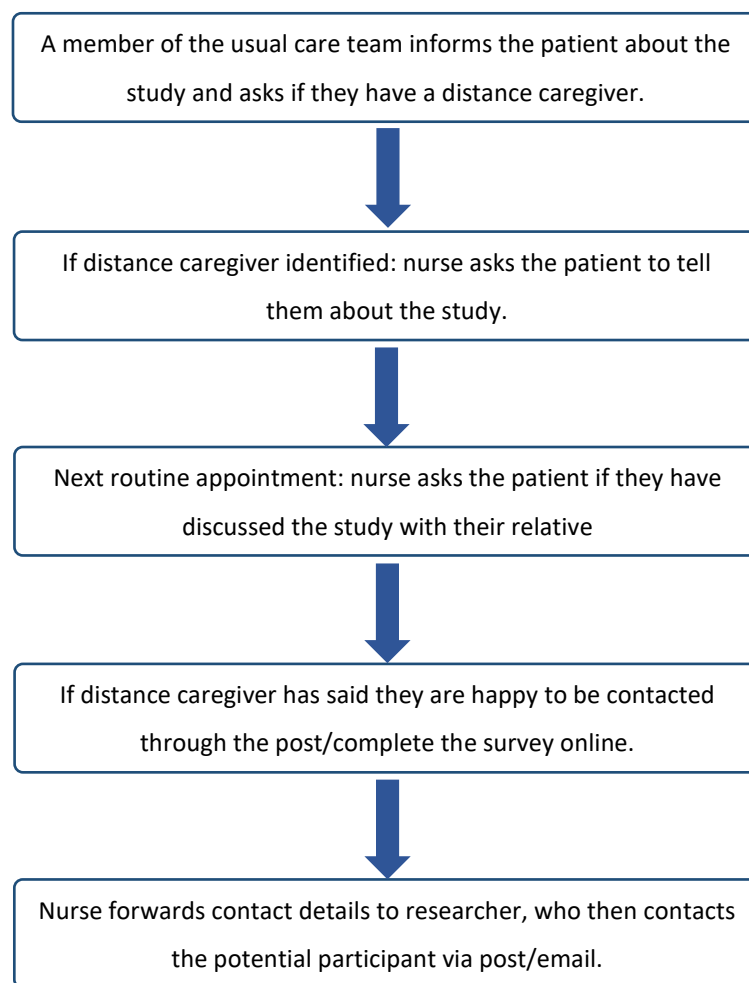
The procedure to recruit participants via PICs was the following:

- 1) A member of the team (usually the nurse) told the patient about the study during a routine appointment, and asked them if they had a relative who lives away and provided any kind of meaningful support, and who would be willing to participate in the study by completing a postal/online survey. The phrasing of the type of participants (distance caregivers) was carefully tailored and tested to ensure that it was easy to understand, whilst being comprehensive enough. In order facilitate the process, leaflets were designed for both patients and professionals that summarised the information about the study; these can be found in Appendix 4.4.

Alternatively, if the care team was already aware that there was a distance caregiver, or such caregiver was present at the time of the appointment, the nurse discussed the study directly with them.

- 2) If the patient indicated that they had a relative providing care from a distance, the nurse asked the patient to tell their relative about the study and ask them if they would mind receiving an information pack and the questionnaire, or receiving the same information via email. The nurse gave the patient time to think about this until the next routine appointment.
- 3) During the next routine appointment, the nurse asked the patient if they had the chance to talk to their relative about the study.
- 4) If the answer was yes, and the relative said that they were happy to be contacted through the post/via email, the patient was asked to provide the postal/email address of the relative to the nurse.
- 5) The nurse then forwarded these contact details to the researcher, who then emailed the relative with a link to the online questionnaire, or sent them the information pack and questionnaire via the post with a self-addressed, stamped envelope.

Figure 4.2: The recruitment process through PICs.



4.4.3. Recruitment of research participants through the community

It was anticipated that carers at a distance would be difficult to identify and contact, since health services usually have limited contact with them. Hence, in order to maximise recruitment for the postal survey, a number of posters (see Appendix 4.3) were displayed in notice boards and websites of community centres, public libraries, local churches, universities (Oxford Brookes University and University of Oxford) (see Table 4.2.). In addition, word-of-mouth was also used to raise awareness about the study.

4.4.4. Recruitment of research participants through social media

A few months after recruitment started, it became apparent that complementary recruitment methods were needed to supplement the already existing ones, which were yielding very few

research participants. After careful consideration, it was decided to use social media as a complementary strategy to publicise the study and maximise recruitment. This was used as one approach to make the questionnaire available online and use social media as an additional avenue to recruit. Further, it was anticipated that distance caregivers would be geographically dispersed, and hence the use of social media to recruit participants facilitated participation by not being limited to a specific geographical area.

Ethical approval was obtained via a minor amendment. This method was combined with the face-to-face recruitment already in place, thus recruitment via PICs or the community continued throughout the study.

Using social media to recruit in palliative care

The use of social media to recruit in healthcare research has been widely reported in recent years, and the use of social media in palliative care research has also gained impetus in recent years (Hopewell-Kelly et al., 2016; Nwosu et al., 2015; Taubert et al., 2014). A recent publication outlined the opportunities of using social media in palliative care research (Casañas i Comabella & Wanat, 2014), including direct access to potential participants and not being limited to geographic proximity, thus enabling the researcher to reach a wider audience of potential participants.

Hence, the recruitment in the community was done via different channels, with an emphasis in social media, but not limited to it, as outlined in the table below. Approval was also granted for all these forms of recruitment, often via the charity's own governance procedures (Cruse UK, Carers UK, NCPC, FCA).

Table 4.2: Channels used to advertise the study in local communities.

Channel	Method
Oxford Daily Info	Weekly advertisement in Volunteering section (twice with paid-for picture).
Parish magazines	Advertisements in a few parish magazines.
Posters at Oxford Brookes University Campuses	Posters on noticeboards and strategic spaces.
Twitter	Regular updates, following relevant Twitter accounts such as charities, and retweets (re-posting a tweet by someone else). The project's Twitter account was linked to the project's Facebook page.
Facebook	Regular updates, 'likes' of relevant posts, and sharing updates with other relevant Facebook accounts such as charities or patient carers Facebook groups. The project's Facebook account was linked to the project's Twitter account.
National Council for Palliative Care (NCPC) (UK)	Advertisement about the study in their website, with link to study/email. Shared info about study also via their Social Media platforms.
Family Caregivers Alliance (FCA) (USA)	Advertisement about the study in their website, with link to study/email.
Cruse Bereavement Care UK	Advertisement about the study in their website, with link to survey. Shared information about the study also via their Social Media platforms (Twitter, Facebook).
Carers UK	Post about the study in their user forums, with link to study.

4.4.5. Recruitment for the interviews

People who completed the questionnaire were asked to provide their contact details if they wished to learn more about the second phase of the study.

People who indicated interest were contacted via email if they had provided one, telephone if they had not, and asked if they would like to be interviewed for the study. The aims of the interview were briefly explained, and after potential participants confirmed their interest, they were sent a consent form through the post with a self-addressed, pre-stamped envelope (see Appendix 4.9).

4.5. Methods of data collection

This section will explain in detail the methods used to obtain data in this study. A survey was used to gather quantitative data, and semi-structured interviews were conducted to generate qualitative data.

4.5.1. Quantitative methods: questionnaires

Questionnaire surveys are a well-established method in palliative care research (Addington-Hall, 2007). This method provides a minimally intrusive yet effective way of gathering information about a desired population. An online survey was used to gather information from a larger sample, with the aim to provide a broader context for the interview data. Amongst other things, the survey aimed to quantify the socio-demographic characteristics of participants and the recipients of care, the distance between them, what ICT they used and how often.

4.5.1.1. Development of the questionnaire

Wherever possible, existing validated tools were included in the questionnaire. However, existing tools were not available to answer all of the research questions, hence additional items in the questionnaire were developed based on the literature reviews conducted on distance caregiving and ehealth. These have been presented in chapters 2 and 3 of this thesis respectively. In addition, questionnaires from well-established surveys such as Macmillan's cancer carers survey (Macmillan Cancer Care Support, 2011) and the UK Census (Office for National Statistics, 2011) were examined.

The final questionnaire comprised five sections (see Appendix 4.6):

- A. Section A was a tailor-made questionnaire with the objective of exploring the characteristics of this particular population and the way they provided care. This section included questions around the patient's disease, the level of care required by the patient, what kind of care was provided by the distance caregiver, and how far the caregiver lived from the patient.

- B. Section B collected information on how, if at all, respondents used ICT when providing care from a distance. This section included questions on what device/s were used to provide care from a distance, how often they were used, and how helpful was the use of ICT. Due to the lack of previous studies in this topic in palliative care, the questions in this section were developed for this survey.
- C. Section C contained the HADS, a commonly used, validated research instrument. This instrument is described in detail in the next section.
- D. Section D contained another validated instrument, designed to explore carers' needs: the Family Inventory of Needs (FIN). This instrument is described in detail in later in this chapter.
- E. Section E asked about standard socio-demographic information about the respondent, and included questions about their year of birth, gender, marital and work status, and education level.

The last pages of the questionnaire consisted of a detachable form (section F), where participants were asked if they wished to be contacted to have a telephone interview, and asking them to provide their contact details for this. They were also asked whether they wanted to receive a brief summary of the study findings by the end of the research project.

Sections C and D consisted of two different Patient-reported Outcome Measures (PROMs): the HADS and the FIN. The objectives of these are explained below.

4.5.1.2. The Hospital Anxiety and Depression Scale (HADS)

The HADS was developed in the early eighties by Zigmond and Snaith (1983) and is one of the most commonly used PROMs in healthcare. It has been widely used in palliative care and validated for use with carers in this field (Gough & Hudson, 2009).

It consists of 14 items divided in two categories: depression and anxiety. Each of the items in the two subscales can be scored from 0 to 3. Each section can be used and scored separately, and a combined score can also be generated.

The reasons for the inclusion of this instrument in the questionnaire were:

- It has been validated and extensively used in palliative care settings.
- It provided data on the mental health status (depression and anxiety) in this population.
- The HADS is one of the most well-known and commonly used PROMs in healthcare and health psychology.

4.5.1.3. Family Inventory of Needs (FIN)

There are a number of instruments that have been used to evaluate the needs of family carers in palliative care (Deeken et al., 2003; Hudson et al., 2010b; Ewing et al., 2013a; Ewing et al., 2013b). However, choosing a PROM that was able to capture the needs of *distance* caregivers was of utmost importance for this study, as many of the commonly used questionnaires are designed for carers who provide care locally, and hence many of their items are around such care. Following a comprehensive review of available questionnaires for carers, the FIN (Kristjanson et al., 1995) was deemed to be the most appropriate for this study.

The FIN is a lesser known but promising questionnaire. It explores the needs of family carers and was developed by Kristjanson and colleagues in the mid-nineties (1995). This tool has been used to explore the needs of family caregivers in palliative care (Fridriksdottir et al., 2006; Hannon et al., 2012), and also in diverse end of life populations, such as husbands of women with breast cancer (Kilpatrick et al., 1998), respite care (Skilbeck et al., 2005), and veterans of war with advanced cancer (Hwang et al., 2003).

This instrument comprises 20 items in the form of statements that respondents are invited to score in two ways: first, respondents are asked to rate how important each of the 20 needs was to them on a scale of 0 to 10 (10 being the highest importance); second, they are required to indicate whether the need was met or unmet.

The FIN was included in the questionnaire for several reasons:

- One of the research questions concerned the needs of distance caregivers in palliative care; while this was also explored via the qualitative interviews, obtaining an overall hierarchy of needs for these carers was important to complement this qualitative information, especially since the survey had a larger sample than the interviews.
- The FIN was a validated tool that had already been used in palliative care.
- This instrument was specifically developed for use with carers of advanced cancer patients
- Most of the items were applicable to distance caregivers; this had been a challenge when looking at tools designed to assess the needs of palliative care caregivers, which focused on *local* caregivers only. These instruments were designed to assess the support needs of family caregivers who lived with the patient, and hence comprised questions that may not have been applicable to distance caregiving, for instance: questions around personal time, symptom management, practical help in the home or home equipment (Ewing et al., 2013a); lack of privacy, dependency, impact on social life, the direct strain of caregiving in the home (Zarit et al., 1985; Higginson et al., 2010). Furthermore, many of the items were particularly

relevant to *distance* caregivers, for example items 3, 4, 5, 15, and 17 (see section D of the questionnaire in Appendix 4.6).

In summary, including the FIN and the HADS in the questionnaire allowed the evaluation of both the needs and the emotional status of distance caregivers in palliative care.

4.5.1.4. Versions of the questionnaire

The survey in this study used a questionnaire that was made available in two versions: a paper version and an online version. Both had identical contents and the aim of offering both was to facilitate recruitment.

Paper questionnaire

As explained in section 4.4, participants were initially exclusively recruited via PICs and the community. Hence, the questionnaire was initially designed only to be mailed out as a hard copy only. For questionnaires completed in this way, participants were mailed the following items through Royal Mail:

- Questionnaire (see Appendix 4.6).
- Participant invitation letter (see Appendix 4.5).
- Participant information sheet (see Appendix 4.10).
- Consent form for interview (see Appendix 4.9).
- Self-addressed, stamped envelope in which to return the completed questionnaire and consent form. Survey respondents were only required to fill in the consent form for the interview if they wished to be interviewed.

Online questionnaire

The decision to make the questionnaire available online was made months after the design of the paper version of the questionnaire and its ethics approval, as explained in section 4.4. The online format was different from the paper format in terms of layout, font and colour scheme. However, the questionnaire content (structure, questions, response options, routing) was identical in both versions. Ethical approval was obtained separately for the online questionnaire.

The questionnaire was developed using Qualtrics®, the University's preferred platform for online questionnaire development and distribution. The design of the online questionnaire (font size, colour scheme, and layout) was the University's default. Screenshots showing the online version of the questionnaire can be seen in Appendix 4.7.

4.5.1.5. Cognitive interviews

After the questionnaire was developed based on the literature reviews and other resources, it was tested to ensure that the questions used were appropriate and easy to understand and answer. The method used for this was cognitive interviewing.

Cognitive interviews are a widely used method used in survey research. This type of interview is used to test questionnaires with the target group to ensure that the instructions, questions and response options are not only appropriate but also easy to understand by lay people, hence increasing the likelihood of response rates (Drennan, 2003).

Two rounds of cognitive interviews were conducted during the development of the questionnaire, with a total of 11 people. Both rounds involved people who were caring from a distance, although not necessarily for someone near the end of life. People who volunteer to take part in cognitive interviews are not considered research participants, but advisors instead, hence ethics approval was not necessary for this stage. This is a standard procedure in cognitive testing.

The first round of cognitive interviews took place during the development of the questionnaire, and before submitting it for ethics approval. The second round took place after ethics review, after the Ethics Committee deemed it necessary to test section B of the questionnaire further, because it was around a relatively new topic (the use of ICT to provide care). Consequently, a further five interviews were conducted, and the questionnaire was refined. On submission of this second version, NRES approval was granted. The final version of the questionnaire can be found in Appendix 4.6.

The questionnaire for this study was made available in two versions, on paper and online, and participants were always offered both options.

4.5.1.6. Strengths and limitations of the use of questionnaires

Using a questionnaire to gather data for this doctorate presented a number of advantages. First, the survey made it possible to reach a much larger number of caregivers than would have been possible with interviews alone. Further, by making the questionnaire available online, this doctorate was able to reach participants from around the globe. Second, the variety of questions allowed the collection of considerable information on a number of areas (caregiving patterns and tasks, use of ehealth, caregiver burden, emotional status, sociodemographic characteristics), which would have been extremely difficult to obtain via other methods in the same amount of time. Third, by using a questionnaire the potential participant had the freedom to respond in their own time, with less burden than an interview. Finally, including previously validated instruments in the questionnaire

(see sections 4.5.1.2. and 4.5.1.3.) permitted the comparison of the data generated with previous studies that had used the same tools.

Despite being a commonly used method in palliative research, surveys are not exempt from limitations. One of the main limitations of using a questionnaire is that the data obtained are limited to the questions asked, as there is little or no scope for answers outside the questions. Second, by using a postal/online questionnaire instead of administering it face to face, it was not possible to clarify any doubts respondents may have had when reading the questions. Third, people receiving the questionnaires were able to decide whether to complete and return them or not, and as such were self-selected. This may have biased the sample, as participants who chose to complete the questionnaire may have a different profile to those who did not. Finally, questionnaire development entails a considerable investment of time, even more so when cognitive interviews are included in the process.

4.5.2. Qualitative methods: semi-structured interviews

Interviews are a commonly used methodology in health and social research, and have been praised as a method to elicit data in palliative care research (Payne, 2007). There are a variety of approaches to interviews, ranging from completely open interviews to structured interviews. In unstructured interviews the researcher barely intervenes. At the other end of the spectrum, in structured interviews the researcher follows the interview schedule composed by a list of questions asked in a specific way. These interviews use prompts (which are specifically introduced in the conversation by the researcher, and not necessarily part of the natural flow of the conversation) and probes (responsive to the flow of the conversation, and used to encourage the participant to expand on certain topics of interest) (Green & Thorogood, 2004; Legard et al., 2003). Between these two extremes is the 'semi-structured interview', used in this study. Green and Thorogood (2004, p. 80) provided the following definition of semi-structured interviews:

In a semi-structured interview, the researcher sets the agenda in terms of the topics covered, but the interviewee's responses determine the kinds of information produced about those topics, and the relative importance of each of them.

Qualitative interviews were used in this study to explore the topic in greater depth and to add richness to the survey findings. Using semi-structured interviews allowed in-depth exploration of what participants felt were their needs, asking them about their experiences of distance caregiving in a meaningful way. Further, this study was addressing a sensitive topic, as participants were providing care to a relative near the end of life, and hence the topic was well suited for semi-

structured interviews. Exploring this topic exclusively through a questionnaire would not capture the detail and depth of people's experiences.

4.5.2.1. Development of the interview topic guide

The interview topic guide was informed by the study objectives and the literature reviews undertaken about family carers in palliative care, distance caregivers, and ehealth. In addition, the results from the survey during the first stages of the study influenced the interview questions. For instance, if a considerable number of respondents highlight a particular issue, this was included in the interview. Ultimately, the interview questions were structured in two parts (see Appendix 4.8).. Part one of the interview was focused around the kind of care that distance caregivers provided, how they provided this care from a distance, and what their experiences and needs were. Part two of the interview focused around whether they used ICT to provide care from a distance, and what their experiences were on this. Throughout the interview, great care was taken to ensure questions were asked in a sensitive manner, and to strike a balance between asking specific questions and allowing the interviewee to freely reflect on the questions asked.

Sensitive interviews

This study explored issues around end of life and what that means to their family caregivers; this is a sensitive topic, as participants are exposed to a difficult time in life where their relative is gravely ill. This was taken into account not only during the interviews, but also during the design of the study, especially in the development of the survey and the interview topic guide.

Participants were assured that their data would be kept strictly confidential, and would later be anonymised. Additionally, close attention was paid to any sign of distress shown by the respondents during the actual interview, since people becoming emotional during an interview is not uncommon in palliative care. In the instances where participants became emotional, interviewees were reminded that their participation was voluntary and that they could have a pause, or stop the interview altogether. In the one instance where this happened, the interviewee refused and was happy to continue with the interview. At the end of each interview, participants were thanked for their contribution, reminded that they could contact the researcher, should they have any queries, and that they had the contact details for some organisations which could provide support (Carers UK or Cruse UK) in their Participant Information Sheet (Appendix 4.10).

Telephone/videoconference interviews

Given the nature of distance caregiving, it was expected that the sample in this study would be geographically dispersed. Therefore, telephone and videoconferencing were used in conducting the interviews. In the instances where the participants were fairly local, the option of a face-to-face

interview was offered. However, this was rejected in the interviews where it was offered, and participants opted for telephone or videoconferencing.

Whilst not being able to do face-to-face interviews meant that some aspects of communication, (i.e. non-verbal communication, and the subtle effect of face-to-face communication) were lost, doing interviews by telephone/videoconferencing allowed for interviews with participants living in different countries and time zones, which in turn increased access to relevant participants.

Videoconferencing was done using Skype® or Facetime®, depending on the participant's preference. Most distance caregivers that interviewed were already regular users of these videoconferencing platforms, as they used them to keep in touch with the patient. Being able to use videoconferencing for interviews meant that the limitations inherent to telephone interviews could be overcome.

All interviews were being digitally audio-recorded. Video data from teleconferencing was not taped, and this was made clear to participants at the beginning of each interview. The interviews were transcribed verbatim.

Long-distance research interviews

After participants had agreed on being interviewed, a convenient time and date was agreed for the interview. Both the times for the interview and the platform used (telephone or videoconference) were chosen by the interviewee, as the burden of their participation in the study was always kept as minimal as possible. In all but one case where videoconferencing was used, the Wi-Fi connection was good enough to allow a face-to-face, albeit virtual, interview.

In many cases participants lived in a different time zone and there was a significant time difference. Interview scheduling was flexible and interviews were arranged at a time that was convenient to the participant. The same applied to the cases where the participant had a job and could only be interviewed over the weekend. These two factors resulted in a number of interviews being conducted outside office hours.

4.5.2.2. Strengths and limitations of using semi-structured interviews

The use of semi-structured interviews in this doctorate presented some limitations. Similarly to the questionnaire, participants for the interviews were self-selected, as they were free to decide whether they wanted to be interviewed after completing the questionnaire. As such, they may have different characteristics to those who declined being interviewed. Caregivers who were relatively local were offered to have a face to face interview, but all of them opted for telephone, and their answers may have been different during a face to face interview. During the interviews, participants may have been more inclined to give answers which they thought were expected or appropriate. To

minimise this, at the beginning of each interview the researcher explicitly indicated that there were no right and wrong answers, and that the aim of the interview was to understand their personal experience of distance caregiving and the use of ehealth to provide care from a distance.

Overall, the advantages of using semi-structured interviews greatly surpassed the limitations. One of the main strengths of this method was that the interview topic guide could be prepared in advance. This was helpful for a number of reasons. The topics explored were rather specific (especially the elements around ehealth, which could be perceived as somewhat unusual), so having some structure (see Appendix 4.8) helped elicit the data. At the same time, questions were purposely open ended and hence allowed the interviewee to influence the content. Having a loose structure was particularly suitable for telephone interviews. More importantly, participants were only interviewed once in this study, hence obtaining data on the specific topics was crucial. Using semi-structured format facilitated this, as it ensured that a core list of questions was asked in each interview. In turn, this made it easier to compare between cases during the analysis stages.

4.6. Methods of data analysis and synthesis

This section details the methods used to analyse and synthesise the data. First, methods used to analyse the quantitative data collected by the survey will be described. Second, the method used to analyse the data from the qualitative interviews will be presented. The last section of this chapter details how these two types of data were integrated in this study.

4.6.1. Analysis of quantitative data: descriptive statistics

The data from the survey were analysed using descriptive statistics, as complex statistical analyses were not possible due to the small sample size. Categorical variables were presented as frequencies and percentages. The Statistical Package for the Social Sciences® (SPSS) software programme was used to carry out calculations and design Custom Tables used to present cross tabulations.

Before data collection, each of the questionnaire items was assigned to a research question. Variables were recoded for the analysis, for example to create distance groups or age groups.

Questionnaires were only included in the analysis of results if the respondent had answered at least the following five questions:

- 1) Question A3: How is the patient related to you?
- 2) Question A5: For how long have you been providing support, in any way, for your relative?

3) Question A9: How far do you live from your relative?

4) Question A10: How long does it take you to get to your relative?

5) Question A11: How easy is it for you to visit your relative?

Without responses to these questions, it was not possible to answer the research questions of this study.

If a questionnaire was included in the analysis but data were missing from questions other than the required A3, A5, A9, A10 and A11, missing data were excluded from calculations for the other questions. Consequently, tables in Chapter 5 will indicate valid percents, which exclude the missing data and only reflect the results from valid responses. However, missing responses will be included in the tables as a way to show how many responses were excluded from each question.

4.6.2. Analysis of qualitative data: framework analysis

After the interviews were transcribed verbatim, data were entered into the NVivo® software programme, which is specifically designed to facilitate the analysis of qualitative and mixed methods data.

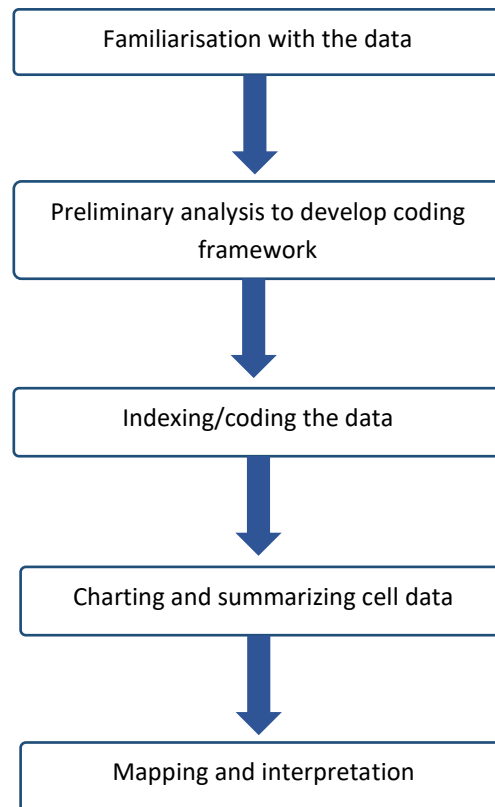
The qualitative data resulting from the semi-structured interviews were analysed using Framework Analysis (Framework). This is a type of thematic analysis used to manage and analyse qualitative data. The rest of this section will explain the origins and methods of Framework, and describe how it was used for the present study.

Framework is a systematic matrix-based analysis method that combines inductive and deductive approaches, and was developed in the 1980s by Jane Ritchie and Liz Spencer, researchers at the National Centre for Social Research in the United Kingdom (Green & Thorogood, 2004; Gale et al., 2013).

The method is based on systematic thematic analysis, which involves summarising, classifying and mapping the data through five interconnected stages, with the aim of scrutinising, charting and sorting the data systematically. This enables the researcher to be comprehensive, and simultaneously compare within and between cases during the analysis stage. Other key features of this method are that it allows the researcher to structure the information very clearly (using matrices), which in turn makes it accessible to other researchers and easily replicable; and it makes it easy to retrieve the information at any point (Ritchie & Spencer, 2002). Framework was chosen for the qualitative analysis of this study because it is a specific method used for qualitative work when the objectives are identified in advance; hence, it allows the analysis of the data based on the

research questions. Framework also facilitates establishing relationships between themes. This method consists of a series of systematic steps (see Figure 4.3).

Figure 4.3: The five stages of framework analysis (Ritchie & Spencer 1994)



Gale and colleagues (Gale et al., 2013) described how they used this method, and operationalised it in similar, although more specific, categories: transcription, where the data are transcribed verbatim and the researcher immerses themselves in the data; familiarisation with the interview, where the researcher re-reads or listens again to the interviews; coding, where the data are coded line by line; developing a working analytical framework, where the researcher collates the coding categories and organises the codes; applying the analytical framework, where the data are indexed using the framework developed in the previous stage; charting the data into the framework matrix, where the data are charted by categories and organised in charts; and interpreting the data.

Following the first stage of transcribing the interviews verbatim, notes were initially taken on paper while reading the interviews (familiarisation with the data). In this familiarisation stage, the researcher also starts the process of conceptualisation, taking notes or marking recurrent key themes, thus identifying a thematic framework.

In the next stage interviews were read again directly in NVivo®, and were coded using the software. Each sentence or group of words was assigned a label that summarised its meaning, that is, it was given a code. In many occasions, a sentence or paragraph was coded with more than one single code, because more than one single concept was identified in it. In addition, the “Annotations” feature in NVivo® was used to write notes, memos or ideas that helped develop the analysis process by reflecting on that particular piece of text. Annotations consisted of a few sentences and did not necessarily apply only to that segment of text, as they could be thoughts about related areas, or memos to consider at later stages. On the other hand, codes were short labels (one or two words) that succinctly summarised what that specific section described, and were as close to the data as possible. Below is an example of data on the left, and the codes that were applied on the right:

Data from interview	Codes
<i>“I’m slightly conflicted as well because I do have a son of 11, and I have three daughters and a grandchild, so I effectively have two lives, and sometimes there is conflict between the two, particularly on time.”</i>	Conflict Children/grandchildren Two lives

Following transcription, familiarisation, and coding, the fourth stage of the process of data analysis involved developing an initial conceptual framework (developing a working analytical framework, as per Gale et al., 2013). This consisted of grouping the codes already identified into categories. Each category was a group of codes that were deemed to be interconnected because they related to the same or similar idea or concept. Through this iterative process, a number of tables were created in Word® organising the codes into categories. These tables were a simple yet effective way to develop the categories, and a few different combinations were considered until a working analytical framework was achieved that represented the data from the interviews. Following on the previous example, the codes of “conflict”, “children/grandchildren” and “two lives” were grouped, together with other codes, into a category called “Balancing two separate worlds”.

In the next stage the data were coded systematically in NVivo® according to this working analytical framework: this entailed reading all the data again and applying the coding index (“indexing”). This was an iterative process, as during the reading and re-reading new codes were identified, and added to the coding index. While the coding index guided the coding of the interviews and provided a framework, flexibility was necessary in order to ensure that the codes were rooted to the data and reflected what the participant was expressing, instead of “forcing” the data to fit into the

framework. To this effect, during the initial stages, each category within the framework contained an “Other” category, and codes that did not relate to any of the existing ones were coded to, and these were later examined. In addition, the working analytical framework was modified and refined as part of the iterative process.

The next stage involved charting the data: summarising the data from the coded interviews into structured charts called framework matrices (Ritchie & Spencer, 2002; Gale et al., 2013). Collating the data in matrices contributed to the analysis by providing a systematic and structured way of looking at the data, sorting it and looking at relationships between codes (for instance, deciding which codes needed to go together in one matrix). The matrices were organised in the following manner:

- One framework matrix was created for each category. The top row of each matrix indicated the codes’ names.
- Each row represented one case, hence each matrix consisted of 21 rows (one per case)¹.
- Each column represented one code.
- Each cell hence contained quote/s from one particular interview about one specific code. Within each cell, each quote was summarised to enable analysis, unless the quote was very short, and therefore did not need summarising. When a quote was seen as particularly helpful to illustrate a theme, this was signalled to aid the future writing of the thesis. In addition, notes (‘annotations’) were entered in the cells when relevant.

Consequently, each matrix contained all the data related to one category. Data could be present in more than one single matrix if it had been coded as two or more codes. Some of the matrices became too cumbersome to be visualised using NVivo® due to their size. In those cases, matrices were exported into Excel® for ease of use.

Similarly to the coding of the raw data, building the matrices was an iterative process and several versions of each matrix were built until the final versions were achieved. Organising and collating the codes and categories into matrices facilitated the next stage of the process (interpretation) by providing a visual structure to the large amount of data. Crucially, in addition to these procedures, the categories and matrices were discussed in supervision sessions, exploring different ways of categorising the data.

Finally, the last stage was to interpret the data: the categories of data in the matrices were reviewed and analysed, searching for patterns, associations and relationships between codes in order to find a

¹ Examples of matrices have not been included in this thesis due to their cumbersome size, as each matrix spans over several pages both horizontally and vertically.

structure. This is the key stage of the analysis, where themes are identified based on the categories. In this study, this was done by printing out the matrices and re-reading the data and the cell summaries; this very often prompted the re-reading of interview sections. Data were also visualised in different ways using NVivo® in order to examine relationships, with concept maps and hierarchical charts. The features of highlighting and coding strips were helpful to work with the data within the individual interviews. However, these were not the final data analysis, but, rather, a way to analyse the data using visualisation as part of the process. This was an iterative process whereby themes were identified by interrogating the data with the research questions. Themes were higher-level concepts in comparison to the categories, which were merely a way to classify and organise the codes. Instead, themes represented concepts that articulated a meaningful element identified in the data in relation to the research questions. For example, the sentence used as an example above was ultimately included in the theme Psychological struggle following its coding and categorisation:

Data	Code	Category	Theme
<i>"I'm slightly conflicted as well because I do have a son of 11, and I have three daughters and a grandchild, so I effectively have two lives, and sometimes there is conflict between the two, particularly on time."</i>	Conflict Children/ grandchildren Two lives	"Balancing two separate worlds" Later changed to: "Contrast between two separate worlds"	Psychological struggle

Using NVivo® throughout this process provided flexibility, as data could be coded and recoded very quickly without altering the main body of the original interview, and different versions of the dataset could be saved which allowed for easy comparisons. It also facilitated retrieving data at later stages, especially when preparing the matrices, and looking at data in different ways (matrices, charts, concept maps). While using NVivo® as a tool during the qualitative analysis stage in this PhD was a very helpful addition, software is neither necessary nor essential for this type of analysis.

Rigour

Green and Thorogood (2004) discussed the issue of rigour in regards to the analysis of qualitative data. They proposed a number of features that rigorous analysis should present (Green & Thorogood, 2004). The first of these features was transparency, which could be done by providing an audit trail of the procedures so that other researchers are able to follow the analysis process. The

second feature they suggested was maximising validity, and they suggested that this could be achieved by presenting the reader with enough context. Third, they proposed maximising reliability, and a number of approaches to it, such as using more than one single analyst or coder, counting the frequency of key codes, and analysing the whole data set. Fourth, they suggested the use of comparisons, both within and between cases, as well as comparisons with other studies. Finally, another possible way of ensuring rigour would be reflexivity around the role of the researcher in the project (Green & Thorogood, 2004).

Rigour and transparency during analysis are core elements of Framework Analysis (Gale et al., 2013). Spencer and Ritchie, the two researchers that developed Framework, provided in collaboration with other qualitative authors a simple yet comprehensive approach to rigour and quality when conducting qualitative research, which consists of four key elements (Spencer et al., 2014):

- Remaining grounded in the data. This refers to the need to ensure that the analysis is rooted in the data, *“rather than simply superimposed”* (p. 280). To this effect, it is necessary to re-visit the data to check that it supports the concepts used (codes, categories, and, later on, themes). This was done during all the stages of analysis, as part of the iterative process, by going back to the interviews often. Throughout the Interview Findings chapter (Chapter 6), quotes from the interviews are provided as examples for each of the themes.
- Ensuring systematic and comprehensive coverage of each unit of data (i.e. each interview). This was done by analysing each interview methodically in the same manner.
- Allowing searches within and between cases, by moving through the whole data set exploring categories and patterns. Framework particularly facilitates this with the use of matrices, which display codes and categories organised by cases, thus making it easier to navigate the data searching for patterns and links.
- Ensuring transparency, so that others are able to follow the process of analysis. The use of NVivo® during the analysis stage of this PhD provided a very helpful way to ensure transparency. For example, using the Annotations feature in NVivo® while coding the interviews helped with reflexivity and transparency, as they were automatically linked to the data and easy to retrieve and review at later stages in the analysis when re-visiting the data.

Other strategies were put in place to ensure rigour throughout the analysis process of this doctorate. Supervision meetings included debriefing sessions following most of the interviews during the data collection stage. The first few interviews were analysed independently by two researchers: the PhD student and the Director of Studies. Each of them coded the interviews separately on paper. Then a meeting was held where the separate coded interviews were discussed line by line. Many of

the codes that had been applied independently matched. Where there was a discrepancy, this was discussed and, following careful consideration, codes were decided upon. As the data analysis progressed, the analytical framework was debated in supervision meetings; through this iterative process, the Word® tables organising the codes were discussed in meetings and via email. Finally, during the interpretation stage the themes were thoroughly discussed in supervision by keeping the research questions at the core of the analysis and by examining relationship trees of the themes.

4.6.3. Mixed methods: combining the qualitative and quantitative data

As stated in section 4.1, this study used a convergent parallel mixed methods study design. Although the quantitative and qualitative methods were used sequentially per case (first the survey, then the interview if agreed), both sets of data (qualitative and quantitative) were collected simultaneously, hence making it a convergent parallel mixed design.

The data from the surveys and from the interviews were not linked to build cases, or influenced each other's analyses in any way. The only way that the survey data was used in the interviews was to corroborate the information and save valuable interview time. For instance, before an interview the questionnaire was checked to gather basic information about the interviewee (who did they care for, what disease did the patient had, how far they lived) and this was quickly confirmed at the beginning of the interview or used as a reference when asking questions. For example, the author would say "In the questionnaire you said that you have been providing care to your Mum who lives far from you, could you tell me a bit about the care you give her from a distance?" This was the only way that the two dataset were linked during this study.

Both sets of data were analysed independently and simultaneously using methods appropriate to the data (descriptive statistics for the quantitative data, and Framework for the qualitative data) as described in the previous section. Then, the results from both strands were used as complementary facets of the same research aims. The Discussion Chapter will address the research questions integrating quantitative and qualitative findings. The information from the qualitative data completed the information from data obtained quantitatively; data from both strands was combined to answer the research questions in a more complete way, since both types of data provided complementary information on the same topics.

4.7. Chapter summary

This chapter has presented details of the methods used in this PhD study.

First, the chapter discussed the research questions and objectives of the study. Second, the rationale to choose a mixed methods design was explained: by combining quantitative and qualitative approaches, a richer understanding of the research problem can be provided, addressing multiple facets of the same phenomenon. Third, the population of interest of this study were described: distance caregivers in palliative care. Participants were identified using a combination of recruitment strategies, including using seven hospices to recruit participants. Social media and the online version of the questionnaire were added to the recruitment strategy at a later stage to overcome the challenges experienced.

The methods of data collection were then detailed in the fifth section. Following the literature reviews presented in Chapters 2 and 3, a questionnaire was developed. The questionnaire was cognitively tested and used in a cross-sectional survey to collect quantitative data around aspects of distance caregiving that were quantifiable, and this included the use of two validated PROMs: the HADS and the FIN. Semi-structured qualitative interviews were used to generate rich data and explore in depth people's experiences of distance caregiving in palliative care. The final section of this chapter provided a comprehensive explanation of the two methods used for data analysis. Survey data were analysed using descriptive statistics in SPSS, with recoded variables and cross tabulations. Interview data were analysed using Framework Analysis. This is a method to manage and analyse data thematically, characterised by its systematic approach and the use of matrices to sort, organise and aid in the analysis of the data.

Chapter 5: Findings from the survey

5.1. Chapter overview

This chapter presents the results from the survey conducted as part of this study. Findings have been organised in five main sections. First, the sample characteristics are described. The characteristics of the patients to whom the participants provided care from a distance are also reported. Second, findings around distance, including how often participants were able to visit the patient in person, and how easy or difficult that was, are provided. This is followed by a section which reports on levels of anxiety and depression in the sample. Fourth, the use of ICT by distance caregivers in their role as carers is explored. Finally, the last section of this chapter presents findings around the needs of distance caregivers in palliative care.

5.2. Sample characteristics

A total of 98 people who were providing care from a distance to a person near the end of life (as described in the Chapter 2 and Chapter 4) answered, at least in part, the survey. Questionnaires were only included in the analysis of results if the respondent had answered at least the five relevant questions indicated in Chapter 4. Consequently, 19 questionnaires with missing data for these questions were excluded, resulting in 79 questionnaires included in the present analysis.

This study is unable to report response rates, due to a variety of reasons. The sample used was a convenience sample: it was distributed in ways that do not allow for this calculation. As explained in Chapter 4, the ethics approval obtained from the University and NRES required that recruitment of participants for this study was not done directly by the researcher, but rather through the healthcare staff that had contact with the patients (who would then inform their distance caregiver about the study) or directly with the potential participants. Similarly, in order to preserve the anonymity of respondents, it was deemed appropriate not to use respondent-unique links². This approach meant that the same generic survey link was used throughout when the survey was advertised in social media outlets (Facebook, Twitter, and others as per the Methods chapter), making it impossible to track down respondents, or to know how many people saw the link but chose not to click on it or complete the survey.

² Respondent-unique links are used to track the respondent: each respondent receives a unique link to the survey.

The small sample size precluded any complex statistical calculations, and thus only descriptive statistics are provided for the survey results. Equally, comparisons between sub-groups were only carried out in the few instances where the figures allowed it.

Table 5.1 shows the characteristics of the sample. The majority of respondents were women (n=58, 82.9%), with an average age of 49 years at the time of completing the survey (mean=49.51, median =52, range 29-63). Most of the survey respondents were between 41 and 60 years old (n=51, 73.9%). The vast majority of respondents were White (n=63, 91.3%), of which almost three quarters were White British. In terms of the respondents' socio-economic status, nearly three quarters of the sample were married or living as married, eight out of ten had a university degree or postgraduate qualification, and over two thirds were employed. Almost half of the sample had other dependents, of which most were children. Only 18 survey respondents were former carers (i.e. the patient was deceased at the time of filling in the questionnaire); the remaining participants were actively providing care. The vast majority of respondents chose to fill in the questionnaire online (n=10 completed it on paper). Sub-group analysis comparing results for former and current carers or online and postal respondents was not possible due to these small figures.

In terms of the geographical distance between the patient and the distance caregiver, the sample was evenly distributed in three distance groups: less than 100 miles from the patient, more than a 100 miles but within the same country, and in a different country. Almost two thirds of respondents lived at least 100 miles from the patient, either within the same country or in a different country from that of the patient. Participants in this study completed the survey from nine different countries: Australia, Austria, Canada, Hong Kong, Republic of Ireland, South Africa, Switzerland, UK, and USA.

Table 5.1: Sample characteristics of survey respondents^a

		n	Valid %
Gender	Male	12	17.1%
	Female	58	82.9%
	Missing	9	
	Total	79	
Age group	18 to 30	1	1.4%
	31 to 40	11	15.9%
	41 to 50	21	30.4%
	51 to 60	30	43.5%
	61 to 70	6	8.7%
	71 and older	0	0.0%
	Missing	10	

	Total	79	
Ethnic groups	White British	50	72.5%
	White – Eastern Europe	3	4.3%
	White – other white groups	10	14.5%
	Black Caribbean	1	1.4%
	Black African	1	1.4%
	Black – other black groups	0	0.0%
	Asian – Middle East	0	0.0%
	Asian – Far East	0	0.0%
	Mixed background	1	1.4%
	Other	3	4.3%
	Missing	10	
	Total	79	
Marital status	Married or living as married	51	72.9%
	Divorced or separated	7	10.0%
	Widowed	2	2.9%
	Single	9	12.9%
	Other	1	1.4%
	Missing	9	
	Total	79	
Other dependents	No	37	53.6%
	Yes	32	46.4%
	Missing	10	
	Total	79	
Type of dependent (only those who said they had other dependent/s)	Child/ren (including disabled)	22	71.0%
	Adult disabled person	1	3.2%
	Other	8	25.8%
	Missing	48	
	Total	79	
Highest level of education	Secondary school	5	7.4%
	University degree	30	44.1%
	University postgraduate: masters	21	30.9%
	University postgraduate: PhD	5	7.4%
	Other	7	10.3%
	Missing	11	
	Total	79	
Employment status	In paid work (full- or part- time)	47	68.1%
	Temporarily off sick	2	2.9%
	Unemployed	6	8.7%
	Retired from paid work	5	7.2%
	Unable to work because of long-term disability or ill health	2	2.9%
	In full-time education	2	2.9%

	Other	5	7.2%
	Missing	10	
	Total	79	
Type of carer	Current carer	61	77.2%
	Former carer	18	22.8%
	Missing	0	
	Total	79	
Questionnaire mode	Online questionnaire	70	88.6%
	Postal questionnaire	9	11.4%
	Missing	0	
	Total	79	
Distance from patient	Less than 100mi	27	34.2%
	More than 100mi within same country	26	32.9%
	Different country	26	32.9%
	Missing	0	
	Total	79	
^a For former carers (i.e. patient died prior to carer participating in the study), characteristics shown were true at the time of the patient's death.			

5.2.1. Characteristics of patients

This section will present the characteristics of the patients to whom the study participants provided care from a distance, and the context where this care took place. Patient characteristics are presented in Table 5.2.

All patients were identified as being near the end of life, as described in the methods Chapter. Half of respondents indicated that they were providing care from a distance to a relative who had advanced cancer. Other disease groups comprised conditions such as dementia, respiratory and heart diseases, and, to a lesser extent, motor neurone disease (MND) and multi-morbidities.

Almost a quarter of survey respondents (24.7%) had been distance caregivers for over five years. Most distance caregivers were providing care to a parent, with the mother being the most commonly reported recipient of care. The remainder was composed by respondents who indicated that the patient was another relative, including nine cases where the patient was either a brother or a sister. Other relationships were also reported, such as the patient being a sister-, mother- and brother-in-law, step father, aunts and a grandmother. A large proportion of patients were receiving care in their own home, and only a small number were in a hospice. The category “other” places of care included another relative’s home (for instance, the patient was living at a relative’s who lived

locally, such as a sibling of the distance caregiver), a housing association house, and university halls of residence in two cases where the patient was a young adult.

Table 5.2: Patients' characteristics^a

		n	Valid %
Main illness of patient	Cancer	38	50.7%
	Dementia	11	14.7%
	Respiratory/Heart disease	13	17.3%
	Other	13	17.3%
	Missing	4	
	Total	79	
Relationship to the distance caregiver (DC)	Mother	37	46.8%
	Father	28	35.4%
	Other	14	17.7%
	Missing	0	
	Total	79	
Place where the relative received care^b	Their own home	46	63.0%
	Hospice	9	12.3%
	Hospital	7	9.6%
	Nursing or residential home	3	4.1%
	Other Please specify	8	11.0%
	Missing	6	
	Total	79	
How long the DC has been providing care from a distance	Less than one year	26	32.9%
	Between one and 5 years	33	41.8%
	More than 5 years	20	25.3%
	Missing	0	
	Total	79	
^a Characteristics were true at the time of filling in the questionnaire.			
^b In cases where the patient had already died, this refers to the place where they died.			

Table 5.3 summarises the type of support patients required, as reported by the distance caregiver. The areas of care are shown for the overall sample of 79 participants, and for participants who were providing care from a distance to a person with cancer. Comparing the data from participants who provided care to a relative with cancer against other diseases was deemed relevant for two main reasons. First, historically palliative care was linked to advanced cancer, and as indicated in Chapter 2 this has now changed and other health problems benefit from this approach. Second, the other

disease groups in the sample were too small to allow for comparisons, however the proportion of cancer patients was around half the sample (see Table 5.2).

Overall, participants indicated that their relative required support most often with the following activities: transport to go on trips or doctor appointments; activities that required leaving the house, such as shopping, collecting prescriptions, and other errands; getting advice and information about the disease, or about support available; and household chores such as cooking, cleaning, laundry or gardening. A large proportion of participants also reported that the patient needed support when talking to healthcare staff on their behalf.

The needs of people with cancer (n=38) were compared to those of people with another condition (n=37) (see Table 5.3). The group of people without cancer included people with conditions such as dementia, MND, chronic obstructive pulmonary disease or multi-morbidities. Non-cancer patients seemed to present higher care needs, as their distance caregivers reported more often that their relative needed support with the following activities: getting advice about their condition and support; making phone calls, writing letters or emails, filling in forms, similarly to getting advice; talking to healthcare staff on their behalf; taking their medication; managing finances; personal care; and needing constant supervision more often. People with cancer were perceived by their distance caregivers as needing support in these areas less often.

Table 5.3: Activities where the patient needs support

		Cancer versus not cancer						Total	
		Cancer		Not cancer		Missing			
		n	Valid %	n	Valid %	n	Valid %	n	Valid %
Shopping, collecting prescriptions, other errands	No	8	22.2%	9	23.7%	0	0.0%	17	23.0%
	Yes	28	77.8%	29	76.3%	4	.	61	77.0%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Transport on trips/to appointments	No	6	16.7%	7	18.4%	0	0.0%	13	17.6%
	Yes	30	83.3%	31	81.6%	4	.	65	82.4%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Cooking, cleaning, laundry, gardening or other household jobs	No	10	27.8%	11	28.9%	0	0.0%	21	28.4%
	Yes	26	72.2%	27	71.1%	4	.	57	71.6%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Getting advice and information about	No	12	33.3%	6	15.8%	1	.	19	24.3%
	Yes	24	66.7%	32	84.2%	3	.	59	75.7%
	Missing	1		0		0	0.0%	1	

their disease, support available	Total	37		38		4	.	79	
Making phone calls, writing letters or emails, filling in forms	No	16	44.4%	12	31.6%	1	.	29	37.8%
	Yes	20	55.6%	26	68.4%	3	.	49	62.2%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Talking to healthcare staff on their behalf	No	14	38.9%	10	26.3%	1	.	25	32.4%
	Yes	22	61.1%	28	73.7%	3	.	53	67.6%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Taking their medication	No	21	58.3%	15	39.5%	1	.	37	48.6%
	Yes	15	41.7%	23	60.5%	3	.	41	51.4%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Home maintenance, repairs, adaptations	No	11	30.6%	11	28.9%	2	.	24	29.7%
	Yes	25	69.4%	27	71.1%	2	.	54	70.3%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Managing finances	No	18	50.0%	17	44.7%	1	.	36	47.3%
	Yes	18	50.0%	21	55.3%	3	.	42	52.7%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Personal care (e.g. washing, dressing, toileting or feeding)	No	17	47.2%	14	36.8%	3	.	34	41.9%
	Yes	19	52.8%	24	63.2%	1	.	44	58.1%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	
Patient needs someone to be with them all the time	No	29	80.6%	24	63.2%	2	.	55	71.6%
	Yes	7	19.4%	14	36.8%	2	.	23	28.4%
	Missing	1		0		0	0.0%	1	
	Total	37		38		4	.	79	

5.2.2. Distance caregiver's relationship to local carers

Most distance caregivers reported that there was at least one person who provided day-to-day care to the patient locally; only in four cases the distance caregiver was the sole carer for the patient, as shown in Table 5.4. Respondents indicated a range of people who provided care locally, with the largest group being a combination of family members (excluding the patient's spouse), followed by a paid carer and the patients' spouse (n=31). The most commonly reported local carer within the family members were patients' daughters (n=23) (see Table 5.4).

Table 5.4: Local carers

		Total	
		n	Valid %
Number of local carers	One local carer only	27	36.0%
	More than one local carer	44	58.7%
	No one locally	4	5.3%
	Missing	4	
	Total	79	
Who was involved in day-to-day care locally			
Patient's spouse/partner	No	48	64.9%
	Yes	26	35.1%
	Missing	5	
	Total	79	
Patient's son/s	No	60	81.1%
	Yes	14	18.9%
	Missing	5	
	Total	79	
Patient's daughter/s	No	51	68.9%
	Yes	23	31.1%
	Missing	5	
	Total	79	
Patient's father	No	71	95.9%
	Yes	3	4.1%
	Missing	5	
	Total	79	
Patient's mother	No	71	95.9%
	Yes	3	4.1%
	Missing	5	
	Total	79	
Patient's brother/s	No	70	94.6%
	Yes	4	5.4%
	Missing	5	
	Total	79	
Patient's sister/s	No	69	93.2%
	Yes	5	6.8%
	Missing	5	
	Total	79	
Patient's friend/s	No	57	77.0%
	Yes	17	23.0%

	Missing	5	
	Total	79	
Neighbour/s	No	57	77.0%
	Yes	17	23.0%
	Missing	5	
	Total	79	
Paid carer (not NHS)	No	43	58.1%
	Yes	31	41.9%
	Missing	5	
	Total	79	
No one was involved in local day-to-day care	No	71	94.7%
	Yes	4	5.3%
	Missing	4	
	Total	79	
Relationship between distance caregiver and local carer			
A relative	No	35	49.3%
	Yes	36	50.7%
	Missing	8	
	Total	79	
A friend of the patient	No	61	85.9%
	Yes	10	14.1%
	Missing	8	
	Total	79	
A private carer employed by the distance caregiver	No	65	92.9%
	Yes	5	7.1%
	Missing	9	
	Total	79	

5.3. Distance from the patient

Overall, almost two thirds of survey respondents had visited their relative during the last six months, despite the majority of them having indicated that they found it difficult or very difficult to visit, and over half of them reported needing to travel for at least half a day or more (see Table 5.5).

The data in Table 5.5 are also presented by distance groups. In terms of how long it took to travel to visit the patient, the group that lived in a different country reported the longest travelling time, and the highest difficulty in doing so, and they were the group that could visit less often. Nine out of ten respondents in the group that lived over 100 miles away from the patient, but still in the same country, indicated it was difficult or very difficult to visit the patient. However, almost two thirds of this group visited at least once a month. Almost two thirds of respondents in the group that lived

less than 100 miles away from the patient also indicated that it took them between one and three hours to get to the patient, and that they found it difficult or very difficult.

Table 5.5: Distance and difficulty to visit

		Distance from patient							
		Less than 100mi within same country		More than 100mi within same country		Different country		Total	
		n	Valid %	n	Valid %	N	Valid %	n	Valid %
Time it takes to get to patient	Less than 1 hour	10	37.0%	0	0.0%	0	0.0%	10	12.7%
	One to 3 hours	17	63.0%	9	34.6%	1	3.8%	27	34.2%
	Half a day	0	0.0%	13	50.0%	6	23.1%	19	24.1%
	More than half a day	0	0.0%	4	15.4%	19	73.1%	23	29.1%
	Missing	0		0		0		0	
	Total	27		26		26		79	
How easy is it to get to patient	Easy	14	51.9%	2	7.7%	1	3.8%	17	21.5%
	Difficult	13	48.1%	24	92.3%	25	96.2%	62	78.5%
	Missing	0		0		0			
	Total	27		26		26			
How often distance caregiver visited patient	Once a month or more	19	76.0%	17	65.4%	10	38.5%	46	59.7%
	Less than once a month	6	24.0%	8	30.8%	9	34.6%	23	29.9%
	Unable to visit last 6 months	0	0.0%	1	3.8%	7	26.9%	8	10.4%
	Missing	2		0		0		2	
	Total	27		26		26		79	

5.4. Anxiety and depression in distance caregivers

This section describes the emotional status of the sample based on the HADS results. Respondents who were actively providing care from a distance (n=61, see Table 5.1) were asked to complete the HADS as part of the survey questionnaire, and results are shown in Table 5.6. Participants who were former carers were not requested to fill in this part of the survey, as it seemed plausible that their mental status may be influenced by their bereavement.

As explained in the Methods chapter, a score between 0 to 7 in each scale is considered normal; a score between 8 and 10 in one of the scales indicates a borderline case in the scale; and a score of 11 or over in either of the scales is considered a case for that scale (depression and/or anxiety).

Only 40 out of 61 (65.57%) eligible participants filled in this part of the questionnaire. A large proportion of the obtained scores indicated some level of depression and/or anxiety. Only two respondents scored below the threshold for anxiety, with a large proportion obtaining borderline or case scores. For the depression scale, three quarters of respondents obtained a score indicating some level of depression.

Table 5.6: HADS scores

		n	Valid %
Depression score	Non-case	10	25.0%
	Borderline	13	32.5%
	Case	17	42.5%
	Missing	21	
	Total	40	
Anxiety score	Non-case	2	5%
	Borderline	25	62.5%
	Case	13	32.5%
	Missing	21	
	Total	40	

5.5. The needs of distance caregivers

As indicated in the Methodology and methods Chapter, survey participants were asked to fill in the FIN questionnaire. The FIN includes 20 statements on different needs carers may have, and respondents are asked to rate each need from 0 (not important) to 10 (very important), and also to indicate whether the need was met or unmet. This section reports these results.

Table 5.7 shows how the needs proposed were scored by the respondents. All needs were scored as relatively important, with the average importance score being 7.87 on a scale from 0 to 10. On average, over three quarters of respondents indicated that their needs were being met.

While table 5.7 provides an overview of the questionnaire scores, the scores have been broken down in different categories in order to provide a meaningful set of results. These are shown in Tables 5.8 to 5.11.

Tables 5.8 and 5.9 report which were the five *most* and *least* important needs, respectively. The needs scored as most important in this study show how information needs are crucial for distance caregivers. It was very important to have their questions answered honestly, to be informed of any changes in their relative's condition, to be assured that their relative was receiving the best possible care, and to know what treatment they were receiving (see Table 5.8). Importantly, the two needs that were rated as most important (having questions answered honestly and being informed of changes in the patient's condition) were also in the group of five least met needs (see Table 5.11).

Table 5.10 reports the needs that participants indicated had been most met. All of them were around information: having explanations in terms that are easy to understand, knowing the names of the healthcare staff providing care to their relative, and information around the treatment the patient is receiving.

Table 5.9 shows the needs that distance caregivers in this study scored as least important. Many of these needs were around support: having someone concerned about the carer's health, feeling there was hope, and receiving help with the patient's care. The least important need (having someone concerned about the carer's health) was also the least met need (see Table 5.11).

Table 5.7: FIN overall scores

Need	N respondents	Missing	Average importance	N respondents	Missing	% Met	% Unmet
Have my questions answered honestly	66	13	9.29	60	19	73.3%	26.7%
Know specific facts concerning the patient's prognosis	63	16	8.20	57	22	76.8%	23.2%
Feel that the professionals care about the patients	66	13	9.00	56	23	80.4%	19.6%
Be informed of changes in the patient's condition	65	14	9.09	57	22	66.7%	33.3%
Know exactly what is being done to the patient	64	15	8.38	53	26	84.6%	15.4%
Know what treatment the patient is receiving	66	13	8.56	54	25	83.3%	16.7%
Have explanations given in terms that are understandable	65	14	8.34	56	23	89.3%	10.7%
Be told about changes in treatment plans while they are being made	65	14	7.84	55	24	78.2%	21.8%
Feel there is hope	64	15	6.45	50	29	76.0%	24.0%
Be assured that the best possible care is being given to the patient	66	13	8.81	54	25	79.6%	20.4%
Know that symptoms the treatment or disease can cause	66	13	8.11	57	22	80.7%	19.3%
Know when to expect symptoms can occur	65	14	7.70	54	25	74.1%	25.9%
Know the probable outcome of the patient's illness	64	15	8.07	58	21	79.3%	20.4%
Know why things are being done for the patient	65	14	7.89	51	28	86.0%	14.0%
Know the names of health professionals involved in the patient's care	66	13	7.66	53	26	86.8%	13.2%
Have information about what to do for the patient at home	63	16	7.37	50	29	76.0%	24.0%
Feel accepted by the health professionals	66	13	6.96	53	26	75.5%	24.5%
Help with the patient's care	66	13	7.21	50	29	78.0%	22.0%
Have someone be concerned with my health	64	15	5.00	46	33	60.9%	39.1%
Be told about people who could help with problems	65	14	7.47	52	27	63.5%	36.5%

Table 5.8: FIN: five most important needs

Most important needs	N respondents	Missing	Average importance	N respondents	Missing	% Met	% Unmet
Have my questions answered honestly	66	13	9.29	60	19	73.3%	26.7%
Be informed of changes in the patient's condition	65	14	9.09	57	22	66.7%	33.3%
Feel that the professionals care about the patients	66	13	9	56	22	80.4%	19.6%
Be assured that the best possible care is being given to the patient	66	13	8.81	54	25	79.6%	20.4%
Know what treatment the patient is receiving	66	13	8.56	54	25	83.3%	16.7%

Table 5.9: FIN: five least important needs

Least important needs	N respondents	Missing	Average importance	N respondents	Missing	% Met	% Unmet
Have someone be concerned with my health	64	15	5	46	33	60.9%	39.1%
Feel there is hope	64	15	6.45	50	29	76.0%	24.0%
Feel accepted by the health professionals	66	13	6.96	53	26	75.5%	24.5%
Help with the patient's care	66	13	7.21	50	29	78.0%	22.0%
Have information about what to do for the patient at home	63	16	7.37	50	29	76.0%	24.0%

Table 5.10: FIN: five most met needs

Most met needs	N respondents	Missing	Average importance	N respondents	Missing	% Met	% Unmet
Have explanations given in terms that are understandable	65	14	8.34	56	23	89.3%	10.7%
Know the names of health professionals involved in the patient's care	66	13	7.66	53	26	86.8%	13.2%
Know why things are being done for the patient	65	14	7.89	51	29	86.0%	14.0%
Know exactly what is being done to the patient	64	15	8.38	53	26	84.6%	15.4%
Know what treatment the patient is receiving	66	13	8.56	54	25	83.3%	16.7%

Table 5.11: FIN: five least met needs

Least met needs	N respondents	Missing	Average importance	N respondents	Missing	% Met	% Unmet
Have someone be concerned with my health	64	15	5	46	33	60.9%	39.1%
Be told about people who could help with problems	65	14	7.47	52	27	63.5%	36.5%
Be informed of changes in the patient's condition	65	14	9.09	57	22	66.7%	33.3%
Have my questions answered honestly	66	13	9.29	60	19	73.3%	26.7%
Know when to expect symptoms can occur	65	14	7.7	54	25	74.1%	25.9%

5.6. Use of ICT

This section will describe how participants used ICT in their role as distance caregivers. This was explored in terms of providing support directly to their relative, and also in other areas related to their role as distance caregivers. The small number of respondents who completed the survey on paper was very small (n=10), hence precluding comparisons between online and postal participants.

5.6.1. Frequency of use and device used

Almost all participants in this study had used ICT in their role as distance caregivers, with a third using them at least once a week (see Table 5.12).

Table 5.12: Frequency of use

		n	Valid %
Ever used internet in their role as a carer	Yes	68	93.2%
	No	5	6.8%
	Missing	6	
	Total	79	
Ever used the internet in their role as a carer	Every day	6	8.2%
	At least once a week	18	24.7%
	At least once a month	14	19.2%
	Only occasionally (less than once a month)	30	41.1%
	No, never	5	6.8%
	Missing	6	
	Total	79	

Table 5.13 shows what devices study participants used to go online. The most frequently used devices were laptop computers, followed by desktop computers and smart phones, and tablet computers (for instance, an iPad® or a Samsung® tablet). Almost three quarters of participants indicated that they used multiple devices to go online (see Table 5.14).

Table 5.13: Devices used

		n	Valid %
Desktop computer	No	33	47.8%
	Yes	36	52.2%
	Missing	10	
	Total	79	
Laptop	No	23	33.3%
	Yes	46	66.7%
	Missing	10	
	Total	79	
Tablet	No	36	52.2%
	Yes	33	47.8%
	Missing	10	
	Total	79	
Smart phone	No	33	47.8%
	Yes	36	52.2%
	Missing	10	
	Total	79	

Table 5.14: Single device versus multiple device

	n	Valid %
One device	18	26.1%
More than one device	51	73.9%
Total	69	100.0%
Missing	10	
Total	79	

5.6.2. Distance caregivers' use ICT in their role as carers

Distance caregivers in this study used ICT for a variety of tasks whilst providing care to their relative. These can be classified into two main categories: using ICT to seek information online, and using it as an aid to communication. This section presents the survey results in regards to these two aspects of care.

5.6.2.1. Use of ICT for information

Table 5.15 presents the results around how participants used ICT to seek information online for a range of topics. Finding out information about the patient's condition was the ICT activity most

frequently reported. This was followed by finding out practical information for the patient and information about how to provide support to the patient.

Table 5.15: Use of ICT to seek information online

		n	Valid %
To find out information about the patient's condition	No	9	13.0%
	Yes	60	87.0%
	Missing	10	
	Total	79	
To find out about practical aspects for the patient	No	31	44.9%
	Yes	38	55.1%
	Missing	10	
	Total	79	
To book an appointment with doctor/nurse for the patient	No	58	84.1%
	Yes	11	15.9%
	Missing	10	
	Total	79	
To find out information about how to provide support	No	34	49.3%
	Yes	35	50.7%
	Missing	10	
	Total	79	
To share experiences as a carer with other people online	No	57	83.8%
	Yes	11	16.2%
	Missing	11	
	Total	79	

5.6.2.2. Use of ICT as an aid to communicate from a distance

This section reports how participants in this study used ICT as a medium to keep in touch and communicate from a distance, both with their relative and with the medical team treating the relative.

Communication with the patient via ICT

Table 5.16 shows how participants kept in touch with their relative from a distance. In regards to the use of ICT, around a quarter of participants indicated that they used text messages and email to keep in touch, and a fifth used videoconferencing. Just under half of people in the subgroup of participants who lived in a different country reported using videoconferencing to keep in touch with their relative (n=22), and they were also the most frequent users of text messages and email in comparison to the other two distance groups.

Table 5.16: How distance caregivers keep in touch with their relative

		n	Valid %
Phone call	No	8	10.3%
	Yes	70	89.7%
	Missing	1	
	Total	79	
Phone text	No	58	74.4%
	Yes	20	25.6%
	Missing	1	
	Total	79	
Email	No	60	76.9%
	Yes	18	23.1%
	Missing	1	
	Total	79	
Skype®	No	63	80.8%
	Yes	15	19.2%
	Missing	1	
	Total	79	
Visiting in person	No	23	29.5%
	Yes	55	70.5%
	Missing	1	
	Total	79	

Communication with the medical team via ICT

Table 5.17 presents how distance caregivers kept in touch with the medical team providing care locally to their relative near the end of life. The most commonly used method to communicate with healthcare professionals was by telephone. Almost a quarter of participants had used email. None of the participants had used videoconferencing to communicate with the staff treating the patient, and only one survey participant reported using telephone text. Over a quarter of participants indicated that they had not communicated at all with the medical team that was providing care locally to their relative.

Table 5.17: How distance caregivers communicate with the medical team

		n	Valid %
Did not communicate with the medical team		20	26.0%
Communicated with the medical team		57	74.0%
Missing		2	
Total		79	
Medium for communicating			
Phone call	No	33	42.9%
	Yes	44	57.1%
	Missing	2	
	Total	79	
Phone text	No	76	98.7%
	Yes	1	1.3%
	Missing	2	
	Total	79	
Email	No	59	76.6%
	Yes	18	23.4%
	Missing	2	
	Total	79	
Skype®	No	77	100.0%
	Yes	0	0.0%
	Missing	2	
	Total	79	
Meeting them directly	No	38	49.4%
	Yes	39	50.6%
	Missing	2	
	Total	79	

5.6.3. How helpful ICT was

Participants were asked to rate how helpful or unhelpful they had found using the internet overall in their role as carers, *in relation to the patient's needs*. The vast majority of participants in this study found using the internet in their role as distance caregivers helpful, with over a third finding it very helpful (see Table 5.18).

Table 5.18: How helpful ICT was in carer role

		n	Valid %
Overall, how helpful they found using the internet in their role as a carer	Very helpful	22	32.8%
	Somewhat helpful	36	53.7%
	Not very helpful	6	9.0%
	Not at all helpful	3	4.5%
	I don't know	0	0.0%
	Missing	12	
	Total	79	
Overall found ICT helpful or not helpful	Helpful	58	86.6%
	Not helpful	9	13.4%
	Missing	12	
	Total	79	

5.7. Chapter summary

This chapter has presented the quantitative results from this study. It has shown how most of the participants were female, of middle age, married, White British, with high education levels and at work, and were providing care from a distance to a parent. The sample was geographically dispersed and involved respondents from eight different countries. Approximately a third lived in a different country from the patient, a third lived in the same country but at least 100 miles away from their relative, and a third lived fewer than 100 miles. The majority of participants indicated that it was difficult or very difficult for them to visit the patient, but despite this over half of respondents indicated that they visited their relative at least once a month. In the majority of cases there were other carers, often relatives, who provided care locally. Participants in this study presented high levels of depression and/or anxiety as scored by the HADS.

The vast majority of distance caregivers in the study indicated that they had used ICT in their role as carers, often via a combination of devices (for instance, laptop, smart phone and tablet), and that they had found using ICT helpful or very helpful as carers. Distance caregivers used ICT for a range of activities in their role as carers, either for information purposes (for instance, to seek information about their relative's condition), or as an aid for communication with the patient. Only a minority of participants indicated that they used ICT to communicate with the healthcare team.

Results from the FIN instrument indicated the most important needs to distance caregivers were around information, and that the two most important needs (having questions answered honestly and being informed of changes in the patient's condition) were also in the group of least met needs.

Other unmet needs were around support (being told about help, and having someone concerned about the carer's health). Despite this, in most cases participants' needs were being met.

Chapter 6: Interview findings

6.1. Chapter overview

This chapter focuses on the analysis of the qualitative interviews from this study. First, the sample characteristics of the people interviewed will be described. Second, this chapter will present the qualitative findings in three overarching themes: Connectedness, Uncertainty, and Psychological struggle. The last section will summarise the qualitative findings.

6.2. Sample characteristics

Twenty-one people who had experienced providing care from a distance to a relative who was near the end of life were interviewed for this study. As indicated in the Methodology and Methods Chapter, the interviewees were people who had replied to the survey and expressed their wish to be interviewed. The characteristics of the people interviewed were largely similar to that of the people who took part in the survey: most of them were women of middle age who were providing care from a distance to a parent who had cancer and was near the end of life.

Table 6.1 reports the specific characteristics of this sub-group, and provides a brief summary of their circumstances in regards to distance caregiving. Any participant identifiable information has been modified to preserve their anonymity. Text between inverted commas in Table 6.1 denotes a verbatim quote from the participant.

Table 6.3: Characteristics of people interviewed

Participant	Gender	Age	Participant's location	Patient's location	Patient was...	Patient's condition	Circumstances of the carer
Participant I-01	Female	57	UK	UK	Mother	Multi-morbidity	Moved away for work 30 years ago. Started providing care five years ago. Father (patient's husband) died recently. Has adult children. Brother provides care locally and visits during weekends.
Participant I-02	Female	57	USA	UK	Father	MND	Her husband was transferred to Arizona due to work three years prior to the interview and she went with him. This was shortly after her mother died. Sister provides care "locally" but lives two hours away from the patient by car.
Participant I-03	Female	58	Australia	UK	Mother	Cancer	Moved to Australia 35 years prior to the interview because she married an Australian man. Her father and two brothers who provide care locally live in the UK.
Participant I-04	Female	57	UK	UK	Mother	Cancer	Moved to London for work as a young adult. Single with no children. Left work 15 years prior to the interview in order to provide better care to her mother by being able to travel often. Sister provides care locally.
Participant I-05	Female	58	UK	UK	Father	Cancer	Moved to South England from Scotland as a young adult: "I just moved away from home really." Her father lived with her adult brother who had special needs. Her sister provided care locally.

Participant I-06	Female	61	USA	USA (same state)	Mother	Multi-morbidity	Her mother was very frail at the time. Two sisters and two sister-in-laws provide care, locally and from a distance.
Participant I-07	Female	49	UK	UK	Mother	Dementia	Moved to London following university studies. Only daughter, single, no children.
Participant I-08	Female	57	Austria	USA	Mother	Multi-morbidity	Originally from the USA, moved to Austria to study 46 years prior to the interview. Her brothers and sisters lived in different states in the USA and UK, and they all provided care, either locally or from a distance.
Participant I-09	Female	63	Republic of Ireland	UK	Mother	Cancer	Moved to Ireland 21 years prior to the interview, as she married an Irish man. Has young adult children. Her sister and father provide care locally.
Participant I-10	Female	57	Northern Ireland	UK	Son	Cancer	Son moved to the UK for work as a young adult, and had two very young children (the participant's grandchildren) when he died.
Participant I-11	Female	30	Hong Kong	UK	Father	Cancer	Transferred to Hong Kong for work three years prior to interview. Her brothers provided care locally, as well as her mother, who was separated from the patient but had remained on good terms.
Participant I-12	Female	51	UK	UK	Father	Cancer	Moved away to study, later on moved to Scotland where her partner had gotten a job. The only child and main carer. Local friends and the patient's goddaughter provided support locally, as well as private carers.

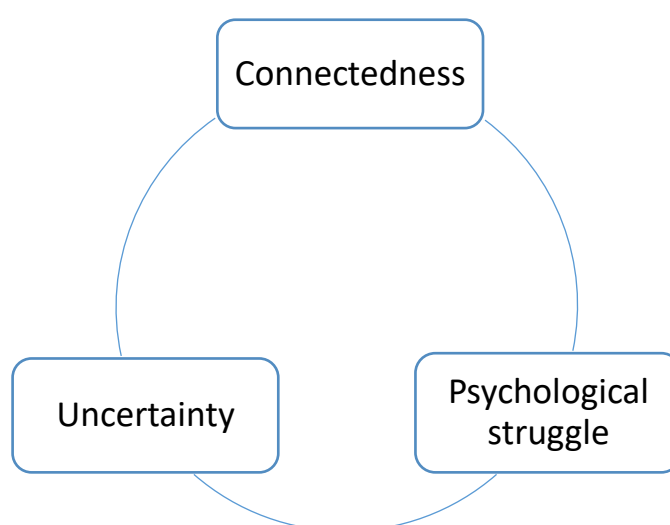
Participant I-13	Female	50	USA	UK	Brother-in-law	Cancer	Moved to the USA with her husband 18 years prior to the interview, initially to take a sabbatical year after selling the family business, then “just stayed.” Provided care from a distance together with her husband (patient’s brother). Patient’s nephews provided care locally.
Participant I-14	Female	51	Belgium	UK	Father	Cancer	Moved to Belgium 25 years prior to the interview because she married a Belgian man. An only daughter, her mother died when the participant was in her mid-twenties, which meant she and her father became very close. Married with two young children.
Participant I-15	Female	48	UK	UK	Mother	Diabetes	Moved to Scotland from England following her husband’s relocation for work six years prior to the interview; before this she lived very near the patient. Brother provided care locally.
Participant I-16	Female	62	Florida, USA	California, USA	Mother	Multi-morbidity	Sisters and other family members provide care locally. Parents moved to California to retire.
Participant I-17	Female	42	Australia	UK	Mother	Cancer	Moved to Australia ten years prior to the interview, seeking a “better standard of living and quality of life”. Her brother lives locally and provides care.
Participant I-18	Male	52	UK	UK	Mother	Cancer	Moved away to study as a young adult, three decades prior to the interview. Married and with two young children at the time of the interview. His father was suffering from dementia when his mother died.

Participant I-19	Female	62	Canada	UK	Mother	Cancer	Moved to Canada 33 years prior to the interview, because she wanted “to visit the country” as her brother already lived there. Her free-lance job meant that she could spend relatively long periods back in the UK, up to two years on one occasion.
Participant I-20	Male	64	UK	UK	Father	Dementia	Moved away to go to university as a young adult. Only son, paid carers provided care locally. Divorced, has an adult daughter.
Participant I-21	Female	52	UK	UK	Mother	Cancer	Moved away after her divorce, 12 years prior to the interview. Her sisters provide care locally.

6.3. Overarching themes

Three overarching themes were identified upon the analysis of the qualitative data: connectedness, uncertainty and psychological struggle (see Figure 6.1). The challenges posed by the geographical distance between the distance caregiver and their relative permeate all three themes. Equally, very often interviewees explained how they used ICT in their role as carers, either to actively provide care from a distance, or for activities directly related to their situation as distance caregivers. This section will present each of these themes.

Figure 6.1: The three overarching themes



6.3.1. Connectedness

All participants in the interviews expressed a deep connection to their relative, despite the distance between them. Participants kept in touch with their loved one very frequently, in a variety of ways, and not only provided care but also shared a strong bond with their relative, who was in most cases a parent (see Table 5.1 in Chapter 5, and Table 6.1 in the present Chapter). This emotional connection was also extended to the local carers, who were very often siblings to the distance caregiver. Further, many participants kept in touch with the healthcare staff providing care to their relative. This section will detail the sub-themes identified around connectedness: feeling connected to the patient despite the geographical distance; providing care from a distance; and needing to “be there in person.”

6.3.1.1. Feeling connected to the patient despite the geographical distance

All study participants felt a close emotional connection with their families despite the geographical distance between them, and this was demonstrated by not only keeping in touch, but also with a strong sense of closeness:

“The distance is only physical, in that I moved to Australia [from UK] as a young woman and I live here with my family.” [patient in the UK] Participant I-03

This section presents the many different ways in which distance caregivers in this study kept their connection with their relative and with those around them, both with other relatives or with the healthcare staff that were providing care locally.

Keeping in touch with the patient

All distance caregivers in this study kept in constant communication with their relative who was near the end of life. This was in many instances done via telephone, but all participants used ICT to keep in touch and communicate with the patient in many different ways in addition to traditional telephone calls. Email, text messaging and videoconferencing were all discussed in depth during the qualitative interviews.

Participants very often explained how they used email to keep in touch on a day-to-day basis with the patient. In some cases, this was also used as a substitute to verbal communication. The quote below is from a participant who explained how email was a helpful means of communication with her brother-in-law, and how it helped overcome communication barriers stemming from the patient's condition:

“Because of his complications after his laryngectomy he can't speak right now, so we have to use email. We were trying for a while to phone, and that worked for a while, but now, for the last few months, he can't speak at all. So it's e-mailing every day, just as a general psychosocial support for him.” Participant I-13

Equally, the use of email could become difficult due to the disease progression. The quote below is from a daughter who talks about how her father was slowly losing his ability to speak due to advanced MND highlights this challenge:

“It's quite hard, because we are losing a primary means of communication. Now, a backup is the email, I've taken to emailing him most days; just to check in in case there was something he really wanted to say that I didn't understand. Because as I said, he has a tremor. He can

email me a couple of lines, but that will take him half an hour to type. So, email's not easy for him either." Participant I-02

Telephone text messaging was also a popular mode of communication, which allowed relatives to keep in touch frequently and instantly:

"The texting was marvellous, because you knew you could be in touch with her within seconds. So important to stay in touch, so very important." Participant I-19

This was greatly valued by many distance caregivers and seen as a reassurance, especially in an emergency. In many instances, elderly patients also used text messages to communicate:

"My mum too was very, she was good at texting. She learned to text when she was in her eighties. They gave her a mobile phone thinking it would be, you know, just something to stay in touch for an emergency or anything, but she picked up the knack of texting. [...] That was just fantastic for her, it really was, it kept her in the loop." Participant I-19

Using Skype® to talk with the patient

The use of Skype® in this study deserves special attention. A large proportion of carers who lived in a different country indicated that they used videoconferencing platforms to communicate with their relative; these were either Skype® or FaceTime®. The use of such software provided a complementary (and sometimes alternative) way of communicating. Families who used this found it useful in a manner of ways and talked about it enthusiastically in the interviews. The quote below illustrates how an interviewee found it provided her with the ability to see with her own eyes how her father was doing:

"We can speak sort of, as face-to-face as you can do with Skype® and that type of thing. So it's actually quite nice, I can actually, because I, I feel that my, my dad has tried to, at times, protect me from, from giving me the full picture about his illness and I've definitely found that using Skype® or FaceTime®, either of those, is much better, because I'm able to visually see, you know, how he's looking, and so I can generally tell by the sound of his voice and the way he looks, if he's having a good or a bad day, or you know, to try and press him for information on how he's getting on. [Compared to telephone calls] it definitely is much, much better I think." Participant I-11

In some cases, the combination of videoconferencing and a mobile device such as an iPad® allowed for great flexibility:

“And we would put it in the middle of the dining table, and there’d be four of us, and we’d spin it from here to here to here, whoever wants to have a chat has a bit of a chat, no one picks it up, you’re not holding it like this, it just sits on the side in front of you.” Participant I-17

In another instance, a participant explained how she used Skype® to incorporate her grandchildren in the communication with the patient by using Skype®. This was especially meaningful as one of her grandchildren (the patient’s great-grandchildren) is in the autistic spectrum, and the participant felt that being able to interact with this little boy via Skype® reassured the patient and improved the patient’s mood:

“One of the things that I did when my mum was very poorly, I thought it would be very helpful for her to just listen to my grandchildren laughing and giggling [...] because they’re just three and two years old, my grandsons, so they would be giggling on the, on the video, and it just, I don’t know, but a giggling baby is just something to cheer you up, you know. And then we would put them on and [the distance caregiver’s autistic grandson] was just learning to say, “Great-grandma”, so she could actually hear him say Great-grandma [...] Talking to people live brings it so much closer to home, right?” Participant I-19

In another case, a daughter who lived in Arizona and was providing care to her elderly father who had MND and a hearing impairment explained how she was able to share bits of her daily life with her father, because she was able to move her laptop around the house to show him things that did not require sound:

“The other side [of using Skype® on the laptop] is, he can see things here. So, I have two dogs, and my father was very fond of them, and I walk around with my laptop and show him my dogs and show him the weather. So, we can participate a little bit in each other’s lives.” Participant I-02

These examples show how being able to use videoconferencing in an informal way added an additional dimension to communication, by including the relative in seemingly mundane yet meaningful family interactions. Being able to share ‘snippets’ of their daily life with the patient brought a level of intimacy to the relationship that would otherwise be difficult to obtain only with telephone communication.

Skype® also proved a successful way to overcome communication difficulties, as shown in another extract from interview quote above:

“I think for my father [using Skype®] makes a huge difference. It really works much better for him. He’s fairly deaf, and he doesn’t wear a hearing aid. I think he has a speaker attached to his computer and he can hear me really clearly when we are speaking on Skype®. But he can’t hear very well on the telephone. The telephone is quite hard for him; he really struggles to hear people clearly on the telephone. But Skype® is very, very clear, and I think because you get the visual cues.” Participant I-02

The wish to remain in contact via Skype® or other videoconferencing systems with their ill relative included the periods of time when the patient was in hospital. A daughter who was providing care from the USA to her father who was near the end of life in England explained how she felt that, while she could still speak to him over the telephone, Skyping was a preferred method of communication while in hospital in order to be able to keep the same level of care and maintain a close day-to-day relationship, and added a further level of intimacy and sharing. Similarly, a daughter who was providing care from Hong Kong to her father who was near the end of life in the UK pointed out the even more basic need in order to be able to use ICT to keep in touch with the patient:

“When they’re in hospital it’s not very easy to speak with them and provide that emotional care that you would do if you were living locally or were able to visit. Particularly, they don’t have Wi-Fi in hospitals for instance, so you know, so it would have to be spending money on phone calls to try and sort of provide that sort of emotional support. [...] If the hospitals could have Wi-Fi as well that would be great, so then we could also speak with the patients via Skype® or FaceTime®, you know, so you could again have that face-to-face contact, that would be really good.” Participant I-11

The use of Skype® was not always the source of positive experiences, as it sometimes made the disease progression more apparent. In one of the interviews, the participant reported feelings of helplessness when her mother would nod off during a Skype® conversation due to the medication side effects, and she felt she could not do anything about it. Another participant, who lived on a different continent from her elderly father, expressed her concern about a time when her father would no longer be able to use Skype® to talk with her:

“Well, because my father has cerebral palsy, which affects speaking and breathing, and so we’re sort of coming, we are pretty much at the end of him being able to speak, and if we

can't Skype® then... [Tears up and pauses] I'm sorry, I get emotional about it." Participant I-02

Communicating with the local carers

Distance caregivers kept in close touch not only with the patient, but also with local carers. The close bond shared with the relative who was dying was very often extended to other family members, which in this study were usually siblings of the distance caregiver, who were also involved in the provision of care. One of the participants expressed simply yet eloquently how this emotional link prevailed despite having lived far from her family for decades:

"There's nobody more important to me than my family, even though I've lived away for a long time." Participant I-05

In some cases, becoming a distance caregiver had prompted changes in the relationship between siblings, and in many occasions participants felt that distance caregiving had brought them closer to their families. Whilst in very few instances there seemed to be some tension, many times distance caregivers explained how they found that their communication had been affected, even when the relationship was good before the parent became ill:

"I've never spoken to my brother so much in all my life [laughter], as I have in the last sort of six months." Participant I-01

The way in which distance caregivers communicated with local caregivers was strikingly similar to the way they used them to communicate with the actual patient, and included emailing, text messages, and Skype® or other videoconferencing platforms.

Participants often used email to keep in touch with siblings, and this was done in combination with other means of communication such as text messages or telephone, as shown in the quote below, which also illustrates how participants discriminated different ways of transmitting information depending on its gravity:

"I suppose you could say another area of my role, if you like, that I see is to keep my sister up to date with how my mother is, physically, emotionally [...] So, if there is any news, as it were, I tend to contact my sister, quite often by email, just to say 'Such and such has happened', or if I actually wanted to discuss something, then I will phone her. [...] When we only got the news that they diagnosed cancer, and I think I phoned my sister and actually talked to her, because I don't think that is something you should do by email." Participant I-04

In contrast, an only daughter who cared for her father while living in Belgium explained how she found it easier to keep her father's friends updated about the father's situation, even in the final moments, via email, rather than telephone:

"I used [emails] also to keep my dad's friends in the loop, because my dad had a lot of friends, and not just locally. It was a way of just keeping everybody up to date on what was going on, and in his final moments, if they wanted to send an email and say, if you want to say goodbye come now, and that was something I couldn't have done by phone." Participant I-14

Interviewees reported using both text messaging and Skype® as an aid to communication with local carers in a very similar way to how they used it with the patients. In terms of using Short Message Service (SMS, that is, text messages), participants praised the flexibility that texting offered them by being a mobile technology, and its immediacy, as this meant that they could communicate instantly with their relatives across the globe, thus helping them manage the barrier of distance. Skype® was used in a very similar fashion to how it was used to keep in touch with the patient, and in combination with other modes of communication, which this quote illustrates:

"So, she and I Skype® and we email and really for the last three years we've done that all the time 'How's dad? What do you think? Do we need to do this or do that?' So, we do a lot of practical stuff that way." Participant I-02

Communicating with the medical team

The deep connection between distance caregivers and their relative also prompted them to take an active role in terms of the healthcare that the patient received, as a way to be able to them provide support. All participants concerned themselves with the healthcare staff that were directly involved with the patient, and tried to meet the medical teams in person and have face-to-face conversations. They also used ICT as an additional way to keep in touch with the medical team. Many distance caregivers used the telephone to communicate with healthcare staff from a distance, but this proved to be rather challenging in general, as shown in this case:

"It hasn't been easy at all. [...] it's very difficult to get clinicians at a time when they have just stopped, and just able to concentrate on, you know, what your concerns are or what information they have to impart to you. [...] So quite often you can phone three or four times in the same day before you get a clinician. If you phone at the wrong time, somebody will say oh, you know, dad's nurse is Mary and she's setting up a syringe driver, or dad's nurse is

Louise and she's doing the medicines, or dad's nurse is Jane and she's actually gone off the ward at the moment, she's taking a patient to diagnostics." Participant I-05

Others used email communication; this was an effective way of communicating in some cases, and there was a sense of it being the least intrusive way of communicating with a busy clinician. Only a few participants talked about using email to keep in touch with the medical team, but this was always perceived as a positive experience. Participants welcomed situations where email communication was offered, and often saw this as an alternative that preserved the medical team's time, was respectful and less intrusive, and was ideal for non-urgent things. Staff were very often perceived as being very busy and participants indicated that they did not want to disturb them with mundane questions, but equally they felt they needed more frequent updates:

"I'm just conscious that [the specialist nurse] must be so busy; you know...they are amazing and you don't want to take up their time if you don't have to. [...] I'm conscious that she will be summoned by a pager and then there will be, you know; someone calls you, when there's a sense of 'Is there some urgency in the request?' and for the most part, I'm not dealing with a practical urgency, I just want to say 'What about this?' or 'Is that going to happen?' Or 'How about this?', and I'd rather she felt able to respond when she's got time to do it."

Participant I-02

In one instance, email was used as a medium for the patient and the distance caregiver to jointly communicate with the patient's doctor, especially since the patient had a laryngectomy that made speaking challenging. The quote below powerfully illustrates how a distance caregiver and their relative formed a strategic alliance in order to overcome the challenges posed by the distance by using ICT:

"I generally write [the patient] a list of questions which I email him, and basically, because he tells us every day how he's doing, what's going on, so I write a list which I email him, all the things that he should talk to his doctor or whoever he is seeing that day at his appointment, and he prints off that list and he can then just point to the list and the doctor can go through it and get some answers. Other times I've actually emailed the doctors directly, with some questions. [The patient] is not very keen on making his own healthcare decisions, so he's referred the doctors, "Can you speak to [participant] and see what she says?" So then I emailed the doctor and found out more information, because it's difficult for [the patient] to tell us all what's been said [in the consultation], so I've spoken with them, and then formed a view, told [the patient] my thoughts and then he can then make a decision feeling he understands it a bit better." Participant I-13

Email was also perceived as having other advantages, such as providing privacy and a written record of the communication that could be referred to at a later stage, in order to clarify information that was provided at a stressful time, or to be reminded of the time and date when the information was given.

Participants also expressed their frustration at not being able to use email to communicate with healthcare staff, or at it being overly complicated; an example was having to go through a generic email address that the receptionist then distributes by forwarding to the appropriate person. Some distance caregivers were able to bypass this, with mixed results. The quote below is from a participant who, thanks to her non-clinical job in the NHS, she was able to find out the email address of her father's GP. The fact that she dismissed the confidentiality of a non-public work email address highlights how keen this daughter was to get in touch with the doctor. This was her experience:

"I wrote my dad's GP an email, which I sent to her, and then I respectfully waited for a response. And after a week of no response I phoned her, she was indeed a very lovely doctor, but she did explain to me 'We do not communicate with anyone by e-mail, and in fact at this surgery we don't pick up our emails.' So the email that I had sent with all of my concerns in it was lost in the ether. [...] I did ask her if there was a generic email where she would pick up anything, or which could be sent to the receptionist or anything, and she just said 'No', they do not use email communication at all." Participant I-05

Participants also spoke about using Skype® as a way to be present in doctor's appointments with the patient. A participant who lived in the USA while her brother-in-law was receiving care in England articulated this need rather well, especially as the patient's speech was seriously compromised:

"I think one thing that would have been helpful is something like being able to Skype® while we are in certain appointments with the oncologist, just so that we could hear what he was saying. [...] It would have been nice to have been able to be part of the discussion when the discussion was happening rather than just afterwards. I think that would have made a huge difference. [...] I just see us in an appointment with an oncologist or one of the consultants and we just have like the iPad® screen up there and we're like on the third seat. There's the consultants, [the patient] and us there, you know." Participant I-13

The cost of long-distance caregiving

For distance caregivers who lived at considerable distance (for instance, in a different country), and for those with limited financial means, the cost of distance caregiving was a concern added to an

already difficult situation. The financial costs of telephone calls and messages, travelling and accommodation were mentioned.

In some cases, accommodation when visiting in person could be an additional problem for the distance caregiver. The quote below from a mother who lived in Ireland and had to travel to and from England to visit her son who had died from a brain tumour illustrates the financial impact that distance caregiving can have. This participant's experience was a very difficult one, as her son had had three consecutive brain tumours, and she had to travel often from the Republic of Ireland to be with him. This had added severe financial constraints to an already difficult time:

"Well the first difficulty was money, because I didn't, I don't have money [...], so I couldn't afford to stay in, you know, bed and breakfast or certainly couldn't afford to do that, I did obviously do it short term, but I couldn't afford to do it. [...] For any longer than a couple of nights. So that was the first problem. That was helped really by friends not being able to stay, but even in terms of the travelling backwards and forwards. My friends and neighbours were very supportive, one neighbour gave me the use of her car, because my car was so old that it wouldn't really have stood the journey. And another neighbour put quite a lot of money in my account, enough that I didn't have to worry about paying for any of the normal things, it wouldn't have been enough to pay for accommodation but it meant that you know, I could do the travelling, I could get the things that [her son] needed [...]. What do you do when you can't afford commercial accommodation? [...] because of course I didn't know the area, I didn't know anybody." Participant I-10

Additionally, in some instances families decided to sell the family home when it became clear that the patient would not be able to return. This made the travelling situation more challenging, since following the sale the distance caregiver had to find alternative paid accommodation in order to visit their relative, which increased the costs.

Distance caregiving also impacted the carer's finances in regards to lesser expenses. In a few cases, people explained how they or one of their siblings found the cost of international text messages to be a challenge:

"We relied on phone calls and Skype® rather than texting. I think texting is very expensive from country to country, so we didn't really text, no." Participant I-09

"[Used the internet] constantly, really. It was always useful. [Without Skype®] I would have been, you know, sitting on the stairs, sitting in the hallway [next to the telephone] speaking to my sister for however long, and probably aware of the phone bill. I doubt very much that

those calls would have been as lengthy as they are now, and as frequent as they are now, they would have been 'more brief', quite simply I wouldn't have been able to do what I do now." Participant I-05

Some participants indicated that they used free proprietary applications such as iMessage® or WhatsApp®, and these made communication easier by not incurring any costs. Similarly, Skype® and Facetime® were often used as a zero-cost alternative to long distance telephone calls:

"[Skype®] is cheaper as well, because he has the Internet connection at home there."

Participant I-11

Using portable devices to communicate

Distance caregivers in this study did not limit their use of ICT to a single device; in general, they used more than one gadget to go online. Portable devices such as tablets or smart phones allowed participants flexibility in the way they communicated with their relatives, thus influencing the way they interacted and the kind of things that they were able to share from a distance. In many cases, hardware that allowed participants to use video, such as laptops or tablets where video was enabled (as opposed to audio only) was perceived as an advantage in terms of keeping in touch with the patient. One participant explained how using her tablet enabled her to spend more time talking to her mother who lived in a different continent: while her mother was resting in her armchair in one country, she could spend time with her daughter while the daughter performed daily chores in a different continent:

"Because I talk to her on the iPad®, I can carry her round, we can do my chores at the same time, there's nothing stopping me from talking to her for." Participant I-17

This participant felt that, by being able to do this, she could spend several hours on FaceTime® with her mother. This enabled her to share the minutiae of daily chores, thus providing a level of intimacy and sharing on a daily basis that could not be done via traditional communication at such great distance. The same participant also explained how she was able to use two different devices simultaneously:

"When mum first mentioned the Cannabinoid trial, I was talking to her on FaceTime® and got my phone and was googling it at the same time." Participant I-17

Dealing with the time difference

In the cases where there was a considerable geographical distance between the distance caregiver and the patient (for instance, different continents, or different regions of a large country such as the

USA), participants talked about the issues posed by the time difference. Although this is of course related to communication barriers, the difficulty stemmed from the actual geographical distance:

“It’s difficult when you might get a piece of worrying news and you have to wait overnight, you’re sat at work all day while you’re sort of waiting to hear what the news is, with the time difference and things, that’s sort of worrying. And also it’s trying to find time to, if you can only call at a certain time, and that’s within working hours it’s making yourself available for the calls you need to make.” Participant I-11

Other participants who were faced with the same challenge found creative ways to make the most of the time difference, and in some instances the way they used ICT to cope with this additional barrier seemed to be advantageous. A participant who lived in Australia explained how she found a way of coping with this by trying to make the most of her schedule and the time difference in order to provide support to her mother who resided in the UK:

“I’m a morning person, [...] so I’m normally up at about five. At the moment if it’s 5.00am here it’s 7.00pm there, mum is at her worst in the evening, she’s at her loneliest and she’s at her ‘tireddest’, so I try and speak to her in her evening, because that’s time when there’s no one else there. She’s got nothing to look forward to apart from X amount of time of not being able to sleep because she’s got a pain. [...] So I can start speaking to her at 5.00am and I start working at, like this morning I started at eight, I could in theory talk to her for that entire three hours.” Participant I-17

Email was also perceived as an advantage in cases where the geographical distance meant that there was also a time difference. The quote below from a distance caregiver who provided care to her brother-in-law in a different continent talks about this. In this case, the relative was quite frail and verbal communication was challenging, and the time delay also allowed both parties to have additional time to think about what they wanted to communicate:

“The Internet is a wonderful thing, we have a time difference, so I think that’s a real advantage, so [the patient] can email at his time convenience and we can email at our time convenience. We don’t have to consider 8 hours and who am I waking up.” Participant I-13

6.3.1.2. Providing care from a distance

Despite the distance, participants in this study were proactive and forthcoming in their role as carers, and performed a myriad of caring tasks, both from a distance, such as providing emotional or financial support, or coordinating care from a distance, but also in person: most participants made considerable efforts to visit in person and, when they were with the patient, they provided hands-on

care. These could be either in coordination with their siblings or other relative who provided care, or independently. A wide range of caring tasks were described by distance caregivers, and these are presented below.

Coordinating the care provided by others

The coordination of care provided locally to the patient was a salient topic, especially in those instances where the distance caregiver was the only carer for the patient. Participants described experiences of organising and coordinating care provided by other family members, neighbours and friends, or paid carers. This would often involve more than one person, as shown in this quote:

“Making sure that [siblings who live locally] are checking in with different family members as well, just to make sure that [the patient] is getting help with errands and cleaning and things that he finds difficult to do as he doesn’t have the energy to get around to do these things. Calling up my family members just to make sure that he can be collected from hospital if he’s not up to driving back and that they are, they are also aware of the [clinical] trial, when and if it would start and what it involved too.” Participant I-11

This coordination of care was not limited to family members or other lay people; it could also involve healthcare staff:

“But a lot of [the care from a distance] is remotely through other people, and usually by phone. So that would include carers, it includes the pharmacist, it includes the doctors, it includes the hospice where he’s involved, it includes the district nurses, it includes the equipment services, when he’s needed those.” Participant I-05

In some interviews, an element of supervision/control of the care the patient was receiving was made explicit, such as keeping track of medications, or feeling that the care was better if the staff felt that there was an active carer “behind the patient”. This was done in a protective manner, as a way to provide care to their relative, who was perceived as someone very vulnerable:

“Keep up a relationship with [the staff] so that they know that I am her primary carer and that anything that needs discussing, I’m the person that would deal with it. And also to monitor what they’re doing and to make sure that she’s being cared for well by them, you know, just to let them know that I am a constant presence and she’s not just been abandoned there.” Participant I-07

Some of the distance caregivers felt that there was a disconnection between the different healthcare staff providing care locally to the patient, and a few talked about the need for an

individual that would be able to coordinate the care and provide a unified care pathway. The quote below is by a daughter who found it very frustrating to see that the care was not coordinated:

“My dad came home with a DNACPR³, and there’s not even a folder to put it in, it’s in his wallet. [...] Nobody seems to be managing this end of life care process. [...] There’s no communication, [...] so then all of a sudden you’re at home with a scenario where nobody seems to be knowing that dad’s even there. I don’t think the doctor was even informed he was home for about 10 days, until [my sister] had been in touch with her. [...] There’s just a big hole, a big void that people come out into, so that has been very strange for everybody. [...] The carers didn’t even know my dad had an end of life prognosis.” Participant I-05

Many of the interviewees that talked about this expressed their wish for a member of staff that would take the place of coordinating the care provided to the patient, as *“some kind of project manager that would be great, who immediately upon diagnosis you get fed into a system, allocated a project manager”* (Participant I-18). In one case, a distance caregiver providing support from the USA to her brother-in-law in England, gave a very accurate depiction of what she thought was needed, based on the “patient navigator” role that exists in the USA, where she lived. She envisaged a system where an appointed healthcare professional would be the designated person for them to get in touch with, and this person would be in touch with the patient and the family guiding them through the process and coordinating all the other healthcare staff. This was seen as especially useful for distance caregivers, who may not be able to keep up with all the different staff involved in the day-to-day care of their relative.

Organising support locally for the patient

The care provided from a distance was not limited to coordinating or supervising care that was directly related to the patient’s physical health. Participants also aimed to ensure that their relative had the support they needed. This could be as varied as home equipment for the visually impaired, finding a form to obtain a Blue Badge, renewing insurance for the patient, or setting up a Personal Alarm for the elderly. Participants did these online, and in most instances, they were successful. However, their relative success depended greatly on the resources available online. The quote below illustrates a case where the information needed was not available online due to the sociodemographic characteristics of the area:

³ DNACPR: acronym for the medical term “Do not attempt cardiopulmonary resuscitation”, often used in palliative and end of life care settings.

“The least helpful thing has been actually trying to find a cleaner for her in Cornwall from Australia, has been a nightmare, because it’s such a small, older community, they don’t use the Internet as much, it’s still much more cards and yellow pages. That would be the only real thing, I wasn’t able to give her an awful lot of help finding a cleaner.” Participant I-17

Similarly, participants also described using ICT to look up information about directions, local services, opening times of stores, locations of hospitals, and their parking restrictions and prices. In some occasions, distance caregivers found that they needed to look for directions and other information about their hometown when visiting the patient, because they had lived elsewhere for decades:

“It would essentially be mainly for simple practical things, such as finding out contact numbers, finding out locations of clinics, because remember that, because I hadn’t lived in Lincoln since I was 18 and when I was 18 I didn’t drive a car, I really didn’t know, I had forgotten most of the roads, I didn’t know my way around, so despite the fact that I was born there I was having to look up places and names, phone numbers, and so there were lots of practical things like that, looking up.” Participant I-18

Providing emotional support

Providing emotional support from a distance seemed to be a universal task for participants interviewed in this study. Interviewees were clear that frequent, often scheduled, phone calls were purposely a way of providing care, by listening to the patient’s worries, monitoring their emotional status, and providing advice. In a few instances it was felt that this kind of care was the only thing that could be provided from a distance:

“Well from a distance, really it was only support, emotional support. I would phone every single day, I finish [work] at half past two, every day I would come home and I would ring. So depending on how she was feeling, we could speak for five or six minutes, or we could speak for half an hour or sometimes to an hour. So really if I wasn’t over there the only thing I could really do was give her support by talking to her. Emotional support, absolutely.” Participant I-09

The task of emotional support was also provided when the distance caregiver was visiting in person. Regardless of the distance, this was often done in combination with the local carers. However, participants sometimes were the “appointed” person to provide emotional support, even when there were other family members available near the patient, as described in this quote:

“I would call her maybe two or three times a day. [...] And she would probably tell me a bit more about how she actually felt about things than she would feel comfortable telling my

dad [the patient's husband, who lived in the household and provided day-to-day care]. So really, it was a lot of over the phone emotional kind of support. I would be the one that would sort of deal with medical kind of things or the emotional side of things." Participant I-15

Providing legal and financial support

This included things such as getting and using power of attorney, dealing with paperwork, having direct access to the relative's bank account (for instance, by having a card in the account), contributing financially to the patient's care (for instance, paid carers or a nursing home), helping the patient prepare their will or funeral arrangements, or selling the family home when it became clear that the patient would be unable to return to it. Distance added further complications to this kind of support. The quote below is from a daughter who explained the challenges she faced whilst providing care to her father, who was in Scotland, while she was in her home in Belgium:

"I had power of attorney, so all of the things which was relevant, so whether it was paying a bill or whether it was phoning to cancel something, or, they were all the things that I would do when I was in Belgium, like all the paperwork things, I would do when I was away from him. [...] My dad's best friend, we had joint power of attorney, simply because I wasn't always going to be in the country, and couldn't therefore always make on the spot decisions." Participant I-14

Giving hands-on care whilst visiting in person

Distance caregivers did not stop providing the support mentioned above when they were visiting in person; rather, they continued the support they were already providing, and added hands-on care that is traditionally associated to local or live-in carers, such as cleaning the patient's house, cooking, or helping with personal care. For participants in this study, their role as carers transcended geographical distance and was related to their bond to the patient. Hence, they continued with their caring role regardless of being away from or near the patient. In one case, a distance caregiver who lived in the same country as the patient explained how her mother would only do certain activities if she had support from the daughter, who lived at a distance, rather than her son, who lived locally:

"I tend to do, more of the sort of things that my mum thinks are only suitable for a daughter to do. For instance, she goes to, she goes to different outpatient appointments and there is one-, because she has heart failure, there is one where she had to go and have electrodes put on her chest. I have to go and do that one, because she doesn't want my brother to see her without her top on. Whereas she's quite happy for my brother to take her for the warfarin clinics, because all she does is prick her finger. So, we have to factor that in." Participant I-01

The internet as a source of information

It became apparent throughout the interviews that participants used the internet as a source of information in many areas related to caregiving, and in the majority of cases this had been a positive experience. Some interviewees pointed out how using the internet was a natural occurrence for them, and it had helped them in their journey as carers in a positive way:

“I certainly use the Internet. The moment my father was diagnosed with MND, I was reading everything I possibly could about it. [...] And so, yeah, I’ve found that the information that you can find online was very helpful. So, that was very specific. [...] It’s a huge source of information. I just use the Internet, like everyone, I use it all the time for everything. It’s just where I get a lot of information about what’s going on or whatever.” Participant I-02

Positive views were also expressed about using ICT to connect with others and find out information about the patient’s disease, treatment options, side effects and innumerable other aspects of care, and this provided a way to cope with not only the barrier of distance, but also to cope with a very difficult time. One of the participants reflected on how she felt it was, to a certain extent, a natural thing to do, and it reflected a cultural shift where patients and families took a proactive role:

“If the doctor said ‘I’m prescribing this drug’, people would go away and take it without finding out any more about it or about their condition or what they could do to help themselves or anything like that. I think that was maybe the culture, I’m thinking 30 or 40 years ago. Probably because of the internet the culture is to find out a bit more and think about it. Well if you’re that kind of person, there are probably some people who maybe, if they don’t read or write very well, it’s difficult for them, you know, if you have a reasonable education it is a natural thing to do, isn’t it?” Participant I-04

A few people who had found using ICT helpful also pointed out some risks, and how they felt that, when faced with vast amounts of information online, discerning the “good” information from “bad” information available could be challenging.

Finally, a minority of participants also expressed negative views. In a few cases participants pointed out how they felt there was a thin line separating information that was helpful from information that was not helpful, and the overwhelming effect that “too much information” online could have on vulnerable people. In one instance, it was felt that using ICT was a barrier, especially for elderly people:

“It feels disembodied if I’m not speaking face to face or verbally with a carer, because it does feel as though we are not talking about my ill relative, but about something in general.”

Which doesn't seem to apply specifically. The computer does feel like a barrier. [...] It's a part of day to day like for shopping, for context and things like that, but I tend to do it reluctantly. Because it was a learning process for me, and I prefer the old-fashioned way." Participant I-03

Some participants expressed views that were somehow contradictory about how they used the internet in their role as carers. In a few instances, they stated that they did not use the internet in their role as distance caregivers, or that they did not find it helpful. However, at another point in the interview they would give an example of a situation where they used the internet for something related to their ill relative, with positive results. One of the participants implied that she did not use the internet in her role as a caregiver:

"[The patient] has got a hospital appointment at a hospital we've not been to before. So, the first thing I did was look it up on the net to find out a) where it was and also directions and also things like where the disabled parking was and all that sort of thing. So, that's the closest thing I'm going to use the internet for." Participant I-01

However, later during the same interview, the participant explained how she also used the internet to find out about aids for her mother, information about social services, or to help her understand medical terms from doctor letters.

Sharing experiences via social media

The use of social media as a way of sharing one's experience of caring was discussed in depth in a few interviews. Social media was used by participants in these instances in their role as carers (as opposed to their personal or professional lives outside their caring role), and as such this use was for themselves, and often not directly aimed at seeking information for the patient.

A few participants had neutral views on social media, and, while they felt that social media outlets were appropriate for others, they did not feel compelled to use them for a variety of reasons: they preferred to share their experiences face-to-face with friends and family; because they felt they were not part of the "social media generation"; they felt sharing personal experiences online was, as one of the participants expressed, "not their personality type"; they were simply not interested, or were only interested in medical information, rather than anecdotal information; they felt that social media was more appropriate for the patient, rather than the carer, as it was the patient who was experiencing the illness; or it conflicted with their wish not to think about the disease all the time. However, in all instances people were aware of social media forums or chat rooms and had indeed anonymously read messages posted by other users.

Other participants also expressed negative views on social media, and these stemmed from negative experiences of it, particularly experiences reading upsetting posts about the condition, treatments, deterioration and prognosis. In relation to this, an interviewee whose mother had advanced dementia reflected on how shortly after the diagnosis she went online to read some forums and found the content very upsetting. However, as her mother's disease progressed, the use of social media became a very different experience:

"Actually I think maybe it depends what stage they are when you ask them, because [in the earlier stages] I looked and I was so appalled that I just thought, I'm just not going to look at that [...] But equally I found that when I realised, having looked at that two years earlier, that when my mum was getting to be that bad I realised that actually I needed to go back and engage with those people because I wasn't getting practical advice from anybody else. [...] And so I went back to [the same] forum because I was specifically looking for people who had got over that hurdle and I wanted some reassurance from them of how they got over it, and what happened. [...] So I don't regret having seen those things, even when it made me frightened, because at least I knew when to go back and look at it a couple of years later."

Participant I-07

Participants who used social media such as blogs, Facebook®, Twitter®, or charities' own chatrooms were enthusiastic about them. They valued different aspects of social media such as being able to share; receive information from peers who can understand what they are going through and give them "the real thing"; finding out about resources from fellow carers; "giving back" by sharing their own experiences; hoping to inspire and motivate others; and raising awareness of the caregiving experience, or the distances caregiving experience. For participants who used social media, this was seen as a fulfilling experience that had helped them manage this challenging situation. The quote below is from a daughter who provided care to her frail mother who lived in California, while the daughter lived in Florida, and had only started using the online forums of a renowned USA-based charity. She felt that this was a good way to find strength and inspiration by sharing her experience and also reading about others' experiences:

"I like the idea of even being able to support each other and to tell our stories to each other, back and forth, I find that very motivating and supportive. [...] [The forum] it's very friendly, it's very graphic, it's got a lot really nice photos in it. It's very welcoming. There's a lot of...right on the homepage, as soon as you open it up, there are quite a number of quotations, you know, from other caregivers or other family members, saying what it's like to be in this situation. You just think 'Yeah, this is exactly what it's like and this is...I want to

know more about this'. [...] Posts from other users I think would be wonderful." Participant I-06

One of the people interviewed for this study was an only daughter who provided care from a distance to her mother with advanced dementia. This participant had her own blog, and talked about her motivation to blog, and how her role as a blogger had enabled her to establish relationships with healthcare professionals and other carers, and also attend conferences as a carer representative, and to share her experiences with others:

"Now that my mum's in care, my use of the Internet is more to give information and support than to receive it, in that I have my blog and I do respond to people who are like me, who want to ask questions about that or have thoughts. [...] I do still look for help myself sometimes as well. The initial thing that got me into the Internet from this point of view in the first place was probably [an Alzheimer's online forum] which is a forum for family carers to share their own questions and advice, which I found actually very much more helpful than any professional advice, because it is really honest, it's not a PR point of view, it's ordinary people telling what actually happened to them and how they coped with it." Participant I-07

Finally, participants also spoke about how by using social media they realised that their experience was similar to that from other people elsewhere. To a daughter who was providing care from a distance to her father, looking up information online helped her combat her feeling of isolation as a carer:

"I was just frustrated, and it was one of my first things on going on the internet was like Googling 'Help, help my father', something in despair, and up came this blog. And from that I learnt for the first time that there was a whole world of people out there doing the same thing I was. I never, it never occurred to me that there was a whole world of people out there, and so when I hit on that blog it was like, I remember it was like five o'clock in the morning and there were 400 comments from people of all ages, from 90 on down, responding to this blog post. And I realised that it resonated not only with me but with so many people, , that was when I first realised that there were people out there doing, going through what I was going through." Participant I-16

6.3.1.3. Needing to "be there in person"

The emotional connection that distance caregivers felt towards their relative usually translated into a felt need to visit in person. Although the use of ICT for videoconferencing and sending text

messages seemed to somehow 'reduce' the barrier of distance, participants talked about the need to travel to see the patient in person, and that nothing could substitute face-to-face contact:

"Being at a distance, you know, you're not there. [...] I think it's the thing about, not actually being present [...] You can't be physically there." Participant I-02

Often, the urge to visit in person was exacerbated by the patient's deterioration, as illustrated by this quote:

"Now that he's deteriorating a lot, then being at a distance, is hopeless, really. So, in fact, I mean I'm travelling to and from now, because I can't, I can't sit here and you know, just let that happen." Participant I-02

In all cases, the need to "be there in person" with the patient became stronger as they approached the last days of life. Participants had a natural desire to be with the patient during the immediate hours before the patient died, and when the actual death took place, and they had often prepared in advance for this significant journey. The quote below is from a carer who had to fly back to Scotland at short notice when she received a telephone call from the doctor treating her father:

"One of the promises I made to dad was that I would be with him, whenever the end was, I would be there. So when the doctor phoned [...] about half past 11am our time, and as I was on the phone to him I was checking out flights, and I said I can be there at six o'clock in the evening. He said I think you might be too late. They'd only just discovered the brain tumour at this point. You might be too late. So I quickly, I always had a bag sort of ready, so I put the rest of the things in the bag, I grabbed my father's birth certificate, my parents' marriage certificate and my mother's death certificate, because I thought I might need them [...] And the drama started at the airport, there were no flights taking off, and eventually I arrived in Scotland and all the roads were flooded, and I couldn't get to the hospital. But when I arrived he was, he was still alive, and he survived a week, and I spent that week just beside him the whole time [and was with him when he died]." Participant I-14

6.3.2. Uncertainty

The sense of uncertainty seeped through all the interviews. This was a difficult issue to deal with for participants. Participants talked about their feeling of uncertainty about how their relative was really doing, uncertainty regarding when it was necessary to put their own lives on hold to travel to the patient, or uncertainty about how much time their relative had left to live, and the potential arrangements that this would require. Participants who were in paid work also felt the impact of

uncertainty on their jobs. This theme was structured into three sub-themes: uncertainty about how the patient “is really doing”; uncertainty about travelling; and uncertainty about time left.

6.3.2.1. Uncertainty about how the patient “is really doing”

In a few cases, participants talked about the challenges of finding out how the patient “was really doing”, because due to the distance they had limited contact with healthcare staff and hence the clinical information about the patient. Interviewees felt that the distance made it difficult to have an accurate idea of the status of the patient, both physically, in terms of the disease, and emotionally, in terms of the psychological impact that the illness had on their relative. An interviewee explained how she felt she was not getting a clear picture of the patient’s situation:

“She wouldn’t tell me that it was cancer, she would never use the word cancer, it always upset her, so she would refer to this thing in my nose. And so I didn’t always know exactly what was going on, and I would have to e-mail or phone to get more precise information from, from my sister or my sister-in-law. Sometimes they could scan one of the reports and send it through e-mail to show me what, what the results were, or the letters, and they were pretty dismal and upsetting. It was very hard at times to get an idea of exactly what was going on, because mum wouldn’t be, she wouldn’t be wanting to refer to it, but she’d just say I’m getting worse.” Participant I-19

In the instances where people used videoconferencing, it was felt that seeing their relative on the screen was a way to overcome this problem, and gave them a more exact idea about how they were feeling. Regardless, as indicated previously, participants always felt that visiting in person was always the best way to know how the patient was doing.

One of the ways that participants tried to overcome this difficulty was using the internet to search for information about the patient’s condition, be it symptoms, the actual diagnosis, treatment options and their side effects, or the prognosis. This was often used as a supplement to the information provided by the doctors.

However, not all accounts of seeking information online about the patient’s condition were positive. For instance, in cases where the patient’s condition was rare (for example, a rare type of cancer) or where the diagnosis had not been reached yet (for example, doctors were still conducting explorations and it took considerable time to find out the specific diagnostic), participants expressed their frustration at not being able to search for information online. This is illustrated in the quote below, where a participant explained how she coped with that by looking for information about symptoms instead:

“We didn’t know what we were looking for. So that, that was probably the most difficult thing. [...] There was nobody, there was nobody that you could ask, there was no website you could look up and say well she’s got such and such a thing, and you could do this or you could try that, there was none of that, because we just didn’t know what was going on. [...] I would use the Internet for looking up information, like when the sort of, the chronic tiredness and the anaemia started, I started looking up about that. And you know, I would do a general sort of Google research, you know, elderly people anaemia, tiredness.” Participant I-15

Further, in a few instances participants explained how looking up information about the condition online had been upsetting. This was especially relevant when in relation to a bad prognosis. In the quote below, a mother who used to provide care from a distance to her son before he died from a brain tumour, described how finding out information about the condition and prognosis online when her son was first diagnosed was very upsetting:

“Well when he was first diagnosed I looked up his condition, and the statistics were very dire, he was unlikely to live beyond three years, and so on, and I just found that so upsetting I didn’t want to know the statistics. I preferred to live in the present time and if the prognosis was really, really bad I didn’t want to go there until I had to. So I never went back on it again I found it so upsetting.” Participant I-10

Access to information online about the patient

In a number of cases, participants stated their wish to be able to access frequent and specific information about the patient via some kind of online platform, in order to be kept up to date with the health status of their loved one, especially when they were in hospital. A daughter who used to care for her mother, who was in a hospice in England, while she lived in Ireland, explained how she thought an online system that family members could access online would be helpful, especially after receiving a diagnosis of cancer:

“You go in to, you meet the [oncology] consultant, you are in a state of shock, and it would be great, I don’t know, if the information could be shared, you could even get access, I’m not saying to the patient’s records, but access to what went on in the meeting, what’s going to happen next, and it’s all, you have a patient number perhaps, and you can log on from anywhere in the world and find out what’s next for your, for your nearest and dearest, I mean that kind of information would be incredibly powerful I think to the family.” Participant I-09

When asked whether this would be a telephone or an online system, this participant replied:

"I'd say it would have to be online. Yeah, I'd say it would have to be, because I don't really, that's a lot of information for over the phone. At least if it's online you can reread it, you can go into it again, you can digest it in your own time, you can read it when you're ready. I mean that would be amazing, if that kind of information, what happened at the meeting, doesn't just go to the GP, but you know, you can have access to it as a family member."

Participant I-09

Other participants echoed this need without any prompting, and provided rather specific descriptions of how they imagined such a system. A daughter who was providing care from Australia to her mother in the UK stated:

"An online form, where I could check if there has been change in medication or if we have brought in a physio for example, your mother tolerated the new treatment to a certain extent this day. If there was something on a regular basis where I could check and see that the treatment went well or badly, or side effects this weeks, but side effects the following. [...] A regular update." Participant I-03

Another distance caregiver suggested a system where several communication methods would be combined. The quote below is a rather long one, however it shows how participants had a very clear idea of the kind of updates that they would need from a distance and were able to provide a detailed description:

"I think if, as a carer from overseas, you were able to get some sort of update about your loved one, from the medical team. I mean it's difficult, because I think with patient confidentiality, but as long as the patient themselves is happy for the family to have that news, then it would be great if we could have some kind of update. I think my, my dad in particular finds it difficult to talk about progression in his illness, and in some ways it might be able to sort of take some of the difficulty of explaining that away from him, so he doesn't have to tell, keep telling all of us about it, he finds it quite difficult to deal with it, with developments in his illness... And, yeah, I think that that would be useful, personally. [...] I think maybe there was some kind of online function, where, as soon as the online function, portal or whatever it was had been updated, it would generate an e-mail to let you know so that you could go and have a look and see what the update is, and that there was always a telephone number on there that you could call if you were, if you needed more information, that type of thing would work well." Participant I-11

A participant who lived in Scotland and used to provide care to her father who lived and died in the South of England expressed a wish for a very similar system, which she described in detail. This person also considered the potential impact on staff workload, and felt that such a system would be more time-efficient, as the healthcare staff would not need to find the time to answer as many telephone calls from relatives. The same participant also considered potential issues around data protection when accessing medical records online:

“And I did wonder about the password thing at a hospital, because I understand, people phone up, and you could be anybody, you could be anybody. Although you know, why anybody, it’s not like my dad was the Duchess of Cambridge, you know, the local papers will be phoning up⁴ to find out how he is. But I understand data protection, people have rights of privacy and all the rest of it [...] So I don’t know if there’s any kind of way [it can be done]. I mean, again, I suppose it’s the whole issue of consent.” Participant I-12

6.3.2.2. Uncertainty about travelling

Living far from the patient meant that there was always an element of uncertainty about when it was necessary to visit the patient in person. This added tremendous levels of stress to a situation that was already difficult, especially when the patient approached the last stages of life and a trip was necessary at short notice. Participants also spoke about how they tried to be prepared for travelling at any given time, should the patient’s situation require them visiting in person. This was done by keeping pre- or semi-packed suitcases and making sure they had enough money to fund the necessary travels. The quote below by a daughter living in Australia, whose mother (the patient) was in the UK illustrates how some patients coped with this:

“So right now, sitting in my bank account, I have enough money to fly to and from England, I have the money for a return flight sitting in my bank account, I have a purse in my bedside table that has English money from when I was last in England, I have £700 in my purse, sitting there in cash, 700 English Pounds, I’ve got a suitcase which is sitting in the cupboard, it will take me 10 minutes to pack. I could be on a plane within 2 hours from any one time, and I just have to wait.” Participant I-17

The uncertainty about travelling affected in an additional way those participants who had jobs, and they talked about the impact that distance caregiving had on their work. Some participants were

⁴ In 2014, a person called the hospital where the Duchess of Cambridge was admitted and enquired about her health status pretending to be the Queen. This was extensively covered by the media. This interview took place shortly after this event.

able to combine their full-time jobs with their role as distance caregivers; for instance, people who could work remotely or had senior jobs that allowed them for more flexibility. In other cases, the demands of distance caregiving were seen as incompatible with keeping a job:

"I had given up my job when he was first diagnosed, because I needed to know that I needed to be free to leave my home at short notice." Participant I-10

Caring from a distance meant not only that participants had to be available to travel at short notice, but also had to manage expectations from work colleagues as to the progression of the patient. When repeated travelling had been necessary, some participants felt that this also affected the empathy that their managers and colleagues felt for them. This quote from a participant who worked as a nurse and lived around 475 miles away from the patient illustrates this point:

"The impact on my professional life is quite immense. I've gone home to [region] on two occasions now for the weekend, one when my dad took a real deep dive and we were told he wasn't going to make through the next 24 hours, I didn't come home, I was there for another seven days, and then when it all seemed to be stable again back I came, having told work that, you know, that's what it was [...] you come back to your job [...] and it's like, they've stopped asking now. Work have been quite good, but it's really quite difficult to manage."
Participant I-05

6.3.2.3. Uncertainty about time left

In the cases where the prognosis was unclear, or where the patient had outlived the prognosis, the uncertainty had a profound impact on distance caregivers. Participants talked about the lack of information received about the patient's prognosis, and about how long the patient had left to live. This need was exacerbated by the distance, which, as indicated above, seemed to add a further element of uncertainty. People expressed their frustration at what they felt was a lack of information and wished that the medical team had been more explicit with them. This frustration was even more acute when it meant that, by not knowing that the patient was very close to dying, a participant had not made arrangements to be with their loved one at that time:

"At no point did anyone say to me well, you know, your father is, your father's dying [...] Nobody was that frank with me. [...] Nobody actually ever said that to me until the day they phoned me up and he was basically dying, and I was in the wrong place." Participant I-12

One of the distance caregivers interviewed in this study also expressed her regret at not having been given the information timely, as expressed in this quote:

“But what I didn’t know and nobody told me, was that I missed the boat on being able to move him. He was too frail, and after I made all the accommodations to my home to make it so that it would work, with the caregiver and my own family, he passed away. What I didn’t know, no one tells you, and this is a huge, huge problem, is no doctor, and he went to tons of them, told me that his body was kind of shutting down.” Participant I-16

Some participants seemed to cope with it by understanding that predicting how long a patient had left to live is often a difficult task, and one of the interviewees explained how her father had outlived his prognosis by months, but that she was mindful that every individual body reacted differently and that prognosis was very difficult to predict. Understanding this seemed to work as a coping mechanism.

Many of the participants talked about their feelings around the patient’s impending death, and how they attempted to cope with it. In many cases, people interviewed reflected on the experience of awaiting their relative’s passing and how they found this uncertainty very difficult:

“It’s very difficult constantly preparing for death, and a death that hasn’t bloody well arrived on time. You know, it, and I know it sounds horrible, I don’t wish her dead, not at all, and she doesn’t wish to be dead, but none of us are enjoying living with a guillotine hanging over our heads, and it’s been there now for over 18 months, and it just, every now and again it just creaks in the wind, you can hear it, it rattles, and you watch the sun glint off it, and it’s this menacing horrible thing, and it doesn’t fall.” Participant I-17

6.3.3. Psychological struggle

As explained in the section Connectedness, the bond that distance caregivers shared with their loved one was not diminished by the geographical distance. However, the caring experience was greatly shaped by it, and the suffering of participants was evident during the interviews. The third overarching theme in this chapter is the Psychological struggle, and this was organised into five sub-themes: the emotional impact of providing care from a distance; the contrast between the two different worlds (the sick world and the healthy world); the positive aspects of caring at a distance; guilt; and needing support as distance caregivers.

6.3.3.1. The emotional impact of providing care from a distance

Providing care from a distance was not easy for any of the participants in the study. Distance caregiving proved to be a psychologically exhausting task, similar to that of local caregiving, but with an added component of emotional stress that was directly related to being at a distance.

Distance was felt to be a very powerful barrier, and perceived negatively, both in terms of losing the physical connection to the patient, and in terms of added stress to the act of caregiving:

“So I mean I think that’s the big thing about distances, that if you were local, even though it’s still emotionally draining thinking she might be approaching the end, you can still pop in for an hour or two every day and then go home thinking if somebody rings me up in the night and says come quickly she’s fading, you could just put your shoes on and go, and you’d be there in 10 or 15 minutes. You know, in my case, if I go home it’s at least 3 hours from notification for me to get there, and if it’s in the middle of the night or it’s bad weather, you know, that’s placing extra stress on an emergency situation already” Participant I-07

The effect of distance on the emotional status of participants was quite apparent throughout all the interviews in this study. Interviewees talked about how the distance increased the stress they felt about the situation, sometimes to the point where they needed to seek professional help for themselves as carers. This participant provided this account of her emotional state when she was asked how she felt about the distance (patient in the UK, carer in Australia):

“It causes me a level of anxiety, such that I have had to see my own GP to get some strategy for my own mental health to help coping with the anxiety, means that I’m actually becoming to such a stage that I actually need some professional help for strategies to cope at home. The distance at least doubles, and probably triples the anxiety that I feel.” Participant I-03

Feelings of sadness and hopelessness were also described, stemming from the geographical distance and not being able to be with the patient in person. These feelings became stronger as the patient’s condition worsened and it was clear that time was limited:

“My father he’s 90, and he is, he is, kind of been falling apart really; slowly, but steadily. [...]. But it’s hard for me, you know, that he has to do that without my help. [...] I think now that he’s deteriorating a lot, then being at a distance, is hopeless, really.” Participant I-02

Participants found that ICT was helpful to somehow mitigate the impact of distance: on the one hand, physical distance had a very clear impact in all cases and participants felt very frustrated because of it; on the other hand, many participants felt that, thanks to the use of the internet and communication technologies (mobile texting, Skype®), the geographical distance was in some instances perceived as non-existent:

“I think the one thing about the Internet is that the distance is immaterial.” Participant I-05

6.3.3.2. Contrast between two separate worlds

In a few cases, the geographical distance seemed to pose a very palpable barrier between the patient's world, which often was seen as a place of sickness and old age, and the distance caregiver's sphere, which in contrast was felt as a place where health, youth and liveliness resided. It was often challenging for participants to reconcile these two seemingly opposite universes. In the quote below, a caregiver explains how he felt when he visited his parents in the city where he grew up, and the difference between that and the place where he lived with his own family:

"I almost feel as if I was drawn into the world of my mum and dad, and so I always felt as if I entered their world when I visited them." Participant I-18

This participant went on to explain later in the interview how he felt about going back to his home in a different city after visiting his terminally ill mother:

"You know that nothing is changing, but it somehow is reasonably comforting, going back at your own bed and sleeping and waking up in the house where there were no sick people. [...] The fact that they existed in parallel was probably I think a good thing; it was almost as if one wasn't contaminated by the other. So all the misery and sadness of one in Lincoln wasn't really reflected in London. To me that meant that when I got back I felt as though I was going back to another world where things weren't so grim." Participant I-18

6.3.3.3. Positive aspects of caring at a distance

During the qualitative interviews, participants were asked whether they thought there were any positive aspects of providing care from a distance. While many of the participants made it very clear that there was nothing positive about it and seemed surprised by the question, others described positive aspects such as having a buffer and being able to step away from the situation, often associated with feelings of guilt. In all cases where the positive aspect of it was verbalised, there were also feelings of guilt intertwined with it.

Buffer zone

A few patients explained how being physically removed from the situation gave them something similar to a "buffer zone", by protecting them from the daily stresses of providing hands-on care:

"I mean if I compare being here compared to being at home, I think, because I was at home when I was living with my dad, and you're sort of, you're living it day-in, day-out, it can feel, you feel a bit better connected with the situation, and I think because you're there for the ups and downs all the time it can feel quite, quite stressful, and I suppose being overseas, and you're not sort of there day-in, day-out, living through the ups and downs you're a little bit

more removed from the situation. It doesn't stop you worrying at all, you're not sort of living through maybe quite so much the sort of the stressful situations that you were." Participant I-11

The distance also provided them with an opportunity to have leisure activities that they would otherwise not be able to do if they lived with the patient. This participant had a very close relationship with her mother, who was near the end of life, and communicated with her daily and provided different kinds of meaningful support, but was still able to find some positive aspects of being geographically far from her:

"When I finish work and I've got an afternoon off I don't feel obligated to go and visit her, and I don't have to deal with that, I can still do my things and it's very selfish being able to do that. It's quite privileged to be in this sort of situation and still be able to do that. [...] We're still trying to have a life despite the guillotine, and we, I don't think we could do that as well if we were nearer." Participant I-17

Stepping away

A few participants explained how living geographically far from the patient made them feel that they could step away from the disease scenario and used this as a coping mechanism, almost as an escape. While the "buffer zone" was felt as a much needed space to preserve their personal life, being able to step away was perceived as a way to completely remove themselves from the situation even if for a short time, as described in this quote:

"There was also a sense in which it was escape, it was escape from this very grim situation. I mean it would have been probably even worse an experience I think if I had just left the house and gone next door, because there you're essentially, this crushing weight of responsibility just seems to be more acute, at least the perception is that it's more acute the whole time, whereas as soon as I got away I actually felt that somehow I had escaped this situation. It was a strange feeling." Participant I-18

Again, the feeling of living simultaneously in two very different worlds became apparent in the quote above. Similarly, other participants described how they felt that by living at a distance they were relieved from the pressure of having to visit every day in person.

6.3.3.4. Guilt

The positive aspects described were associated with a feeling of guilt, which was a powerful experience for some of the participants in this study. All participants who expressed positive elements of being at a distance also expressed feeling guilty about it. On the one hand, distance

caregivers felt relieved by living far, because, by being physically removed from the place where the patient was ill, this offered them the chance to momentarily “forget” about this traumatic situation. On the other hand, they also felt guilty, because they believed that they should not feel comforted by this, when their loved one was so gravely ill. Some participants also expressed guilt around subjecting their children to this situation, and for having to travel often leaving their young family behind to take care of their ill parent. For participants with small children, guilt linked to the feeling of being divided between these two separate worlds added to the emotional stress:

“In that year I always felt as if I was in the wrong place. When I was with dad, I had to be with dad and I wanted to be with him and I didn’t want to be anywhere else. I was very aware that in the background there were my two young children. And when I was over in Belgium I was delighted to be with my children, but there was always, there was this added tension of every time the phone rang I panicked. [...] So, I combined it just because I had to, I had no choice.” Participant I-14

Many participants were able to cope with guilt by rationalising this emotion and realising they could not change the way things were, and found some comfort in this. This participant in Australia very eloquently explained how she tried to cope with these feelings:

“I feel horrendously guilty all the time, but the end of the day, if I leave here and go back there I lose my job, I lose my home, I lose my life. I can’t do that, and mum wouldn’t ask me to do that, nor expect me to do that. But it does mean that I knocked off at four o’clock this afternoon, I went to see my neighbour, we went and walked her dog on the beach, (35:00) we sat on the beach for 45 minutes, I got home, I was round next door until 10 minutes before you called drinking gin in the sunshine in the pool next door, and I wouldn’t be able to do that with, if I was in the UK. [...] If I was in the UK if I finished work, I would be driving down to see my mum. And I, I’m guilty because I can’t and I’m relieved because I can’t, and I’m guilty because I’m relieved. [...] You can’t fix it, you can’t make it any better, [...] it’s a complete waste of time, and all it is, all it does, and I do, every day, I have guilt, I have guilt a lot of the time, but I try and let go of it as quickly as possible because it’s just destructive.”
Participant I-17

6.3.3.5. Needing support as distance caregivers

The psychological struggle of providing care from a distance to a loved one near the end of life, with the added emotional stress stemming from the geographical distance, and trying to reconcile two seemingly opposite worlds, often took a toll on the emotional status of participants. Many interviewees stressed the importance of surrounding themselves “with a caring environment”

(Participant I-10), or having “a support system” of friends and family (Participant I-06), and ensuring they received help and support from those around them and their wider communities.

In a few cases, it was felt that the healthcare staff that treated the patient were not proactive enough to support the distance caregiver. This could be either the healthcare services available locally to the distance caregiver (that is, in a different area from the patient), or the services local to the patient. The quote below is from a son who found that trying to organise and coordinate care from a distance for his father with advanced dementia impacted his own emotional status:

“This winter I got very miserable, I think mainly because I was trying to ask for help. Not only was no help being provided, but equally no one would refuse to provide the help. As I indicated earlier, that was almost more distressing to me, that someone, because if someone says no, then you can ask someone different, can’t you?” Participant I-20

Some participants expressed their frustration at the fact that support from social services for carers, such as financial or emotional support, was only available locally, and hence they were unable to access this help. For carers who lived at a great distance (for instance, a different country or continent), it was easy to understand that these services were not available to them. However, for those who lived in the same country, within the same healthcare system, even when they lived in close proximity to the region where the patient was, this was seen as very frustrating, especially when no alternative help local to them was offered. This added an additional level of stress for distance caregivers, who in a way were not recognised as carers by neither the services local to the patient, nor the services local to them.

The need for bereavement support

One of the aspects where people felt they needed support was around bereavement; this was brought up by a few former carers (where the patient had passed away before their participation in the study). In the quote below, an only daughter talked about her feelings during the months following her father’s death, after almost a year of travelling back and forth from her current country of residence to Scotland, where she was from:

“I had still felt very much that one day I was in Scotland and I was being the grieving daughter and trying to come to terms with everything, then a few days later I was back in the whole Belgian lifestyle and because people, some knew dad, some didn’t, some didn’t know what to say, as always when somebody dies, some don’t know what to say, some were uncomfortable, so it was very hard being back in my real world, having had such an intense

eleven months before then. [...] It was very hard leaving Scotland, because I was, I was... the last time I had flown over my dad had been alive and now he wasn't." Participant I-14

Again, this quote highlights how distance caregivers felt a stark contrast between the place where they lived (in this case a different country) and the place where their relative had died. The quote also shows how the fact that their loved one had died in a place completely removed from their day-to-day community – “my real world”, as this participant coined it – had an impact on their grieving process.

Some participants whose relative had already passed away expressed their wish for guidance and support on the tasks immediately following a person’s death, as the help available to them locally often would not apply:

"The aftermath and the follow-up, because there is a whole series of things that then happened of course once the person has died, and even that could do with more coordination. I think it's all about support, and people who've never done it before, it's just utterly bewildering the kind of things you have to do." Participant I-18

6.4. Chapter summary

This chapter has presented the qualitative findings from the study. Three overarching themes were identified from the interview data: connectedness, uncertainty and psychological struggle. As shown throughout the chapter, the issue of distance pervaded the experiences of distance caregivers, and in most cases people used ICT as a way to manage and cope with the distance.

The theme of Connectedness analysed how participants felt a deep emotional bond with their relatives regardless of how long they had been living away from their loved one. This overarching theme comprised three sub-themes. The first one was ‘Feeling connected to the patient despite the geographical distance’, which related to the need to keep in touch with the patient frequently and sharing their day-to-day life via ICT. This need extended to keeping in touch with the local carers, who were usually other relatives who lived locally to the patient, as well as the healthcare staff providing care. When participants used ICT, they tended to use more than one device in combination (for instance, email, text messages, looking up information online, and videoconferencing) at once. There were two further issues related to distance in this theme: the financial impact of providing care from a distance, and how distance caregivers coped with the time difference. The second sub-theme was ‘Providing care from a distance’, and showed that participants performed a varied range of tasks in relation to their role as distance caregivers. This included the provision of emotional support to the patient, the coordination of care provided by

others locally, the organisation of practical support for the patient, as well as legal and financial support. These caring activities were not limited to being at a distance. Rather, participants explained how they would provide hands-on care when they visited the patient. A minority of participants also spoke about their use of ICT as distance caregivers for tasks that were not directly related to the patient, such as sharing their experience online via social media, and their general views on the use of ICT for caregiving. Finally, the third sub-theme within this was 'Needing to be there in person': interviewees unanimously felt that the distance was a barrier to the care they provided or wanted to provide, and they all felt that the ideal situation was to be able to be with the patient in person.

The second overarching theme was Uncertainty, and this was connected to the unsettling feeling of uncertainty that participants had in relation to many crucial aspects of their situation. This theme was divided in three sub-themes. The first one was 'Uncertainty about how the patient 'is really doing'', which presented how participants found it extremely difficult to not be able to have an accurate depiction of how the patient was. This was directly related to being far away from them and not being able to see them, or the healthcare staff, face-to-face. Distant caregivers tried to overcome the uncertainty by seeking information online. A few interviewees suggested very specific systems that they would like to see in place in order to be updated about their loved one's day-to-day status. The second sub-theme was 'Uncertainty about travelling', and this analysed how participants struggled to decide when it was necessary to travel to see the patient in person, with the financial and work consequences that this would have. This problem was especially acute when their loved one deteriorated and death seemed to be imminent. Closely related to this, the third sub-theme was 'Uncertainty about time left', which was related to the need of participants to know how long the patient had left to live. While most people understood this was a difficult prediction, they all felt that the uncertainty made the situation worse.

The third and final overarching theme identified was Psychological struggle. This theme encompassed all the emotional conflicts that participants felt in relation to their role as distance caregivers. The first sub-theme was 'The emotional impact of providing care from a distance', which analysed the effect that the distance had on the emotional status of participants. The second sub-theme examined how participants felt that they were living simultaneously in two separate worlds: the world that was their home, with their young families or new countries, and the world where the patient was, which was perceived as a world of disease and consequent sadness. The third sub-theme stemmed from this dilemma, and analysed how some people felt there were 'Positive aspects of caring at a distance', by the distance providing them with a 'buffer zone', and being able to 'step away' from this difficult situation. This in turn generated feelings of 'Guilt', the fourth sub-theme, as

distance caregivers struggled to balance this sense of relief. Finally, the last sub-theme was 'Needing support as distance caregivers', and it looked at the needs for emotional support that interviewees had, especially around bereavement.

Chapter 7: Discussion and conclusions

7.1. Chapter overview

This doctorate aimed to explore the experiences of people who provide care from a distance to a relative near the end of life, and how they use ICT in their role as distance caregivers. Very little is known about this increasingly common phenomenon.

The overarching research questions were:

1. How does being at a distance shape the nature of family caregiving in palliative care?
2. What are the characteristics and experiences of distance caregivers in palliative care?
3. What are the needs of distance caregivers in palliative care?
4. How do distance caregivers in palliative care use ICT in their role as carers?

Chapters 5 and 6 have presented the quantitative and qualitative findings respectively. The present chapter will discuss the use of mixed methods for this research, and how the findings contribute to current theoretical debates. The strengths and limitations of this PhD will also be discussed. The last section of this chapter will present the conclusions of this doctorate, the implications for practice and policy, and recommendations for future research.

7.2. Discussion

7.2.1. Key findings

The key findings from this PhD are discussed in this section. As indicated above, each of the two datasets (quantitative and qualitative) contributed complementary facets of the research questions, and this chapter integrates the two and discusses contribution of the findings to the *status quo* of palliative care.

7.2.1.1. The need for a definition of distance caregiving

As reported in the literature review in Chapter 2, there is not a universal definition of distance caregiving in palliative care. Some studies looked at carers who lived at least 100 miles away from the patient (Wagner, 1997; Koerin & Harrigan, 2003; Harrigan & Koerin, 2007; Mazanec, 2009; Mazanec et al., 2011; Mazanec, 2012) while others categorised this population as living at least one

hour drive away (National Alliance for Caregiving, 2004; Roff et al., 2007; Alzheimer's Association, 2013).

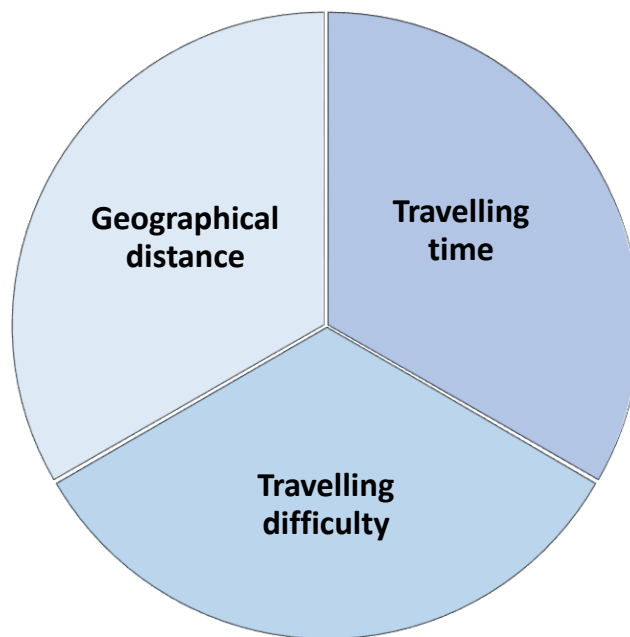
The recruitment strategy used in this study purposely avoided specifying a definition based on distance or travelling time. Instead, the recruitment documents required carers at a distance to “live away from their relative” or “to be restricted in how often they could visit because they did not live nearby” (see poster and leaflets in the appendices of Chapter 4). This was done intentionally in order to let participants decide by themselves whether they were at a distance, rather than being guided by the researcher’s definition of distance.

A third of the participants in this study described themselves as distance caregivers despite living 100 miles or less away from patient. Over a third in this sub-group indicated that it took them under an hour to visit their relative, and almost half of them indicated that it was difficult for them to visit (see Chapter 5). These participants would not have been defined as distance caregivers by previous studies, however they identified themselves as such. The findings from the qualitative interviews further confirmed this view, with participants who lived relatively close to their relative experiencing similar issues around distance to those of people who lived much further away in terms of Closeness, Uncertainty and Psychological Struggle.

A more comprehensive definition of distance caregiving is needed, as current definitions often exclude people who identify themselves as providing care from a distance. A universal definition would make it easier for clinicians and researchers to identify this sub-group of carers, who at present seem to be largely “invisible”, especially when compared to local carers.

In line with the person-centeredness that is at the core of palliative care, such definition should be based on the patient’s and the carer’s perception of how distance affects their interaction. Based on the findings from this doctorate, a universal definition of distance caregiving should encompass the three elements that are important to those providing care from a distance: the geographical distance between the patient and the distance caregiver; the travelling time that it takes the distance caregiver to get to the patient; and level of difficulty that this travelling entails (see Figure 7.1). This thesis has demonstrated how the significance of distance is different for every individual, and that what people perceive as *distance* may be different from what studies propose, especially when basing the definition of distance caregiving on mileage. Hence, the universal definition of distance should be based around the perception of the individual, combining the three elements suggested in Figure 7.1.

Figure 7.1: The three elements that a definition of distance caregiving should encompass.



7.2.1.2. What this PhD adds to this field of knowledge

This doctorate has contributed important advances to the knowledge about the nature of family caregiving in palliative care, and these are presented in this section.

Who provides care from a distance?

As indicated in the introductory chapters of this thesis, literature about distance caregiving in palliative care is extremely sparse. Mazanec and colleagues have done some work around distance caregiving of parents with advanced cancer (Mazanec et al., 2011; Mazanec, 2012; Douglas et al., 2016). Whilst not specifically in palliative care, the findings of Mazanec's PhD dissertation (Mazanec, 2009) are in some aspects comparable to this study, as she used mixed methods to compare a sample of 40 distance caregivers (defined as people who lived over 100 miles away from their relative) against a sample of 40 local caregivers (defined as those who lived 60 miles or less). Mazanec's study initially set out to consider distance caregivers as those who lived over 300 miles from the patient. However, following interviews with participants the cut-off was reduced to 100 miles, and her results stressed the importance of the carer-patient perception of distance. Although she only recruited people who were providing care to a parent and used a very small sample of distance caregivers (n=40), her study reported similar results in terms of sample characteristics: a majority of female carers, of white ethnicity, married, with higher education levels and in paid work. These similarities may be due to the fact that, as shown in the qualitative findings, people often

move to pursue studies or work. Conversely, the average age of Mazanec's sample was younger (38.7 years old, SD 9) than the results of the present study (mean age = 49.51, median age = 52, range 29-63).

How does distance shape the experience of family caregiving?

This study has shown how distance caregivers felt a deep connection to their loved ones regardless of the geographical distance between them. Distance was perceived as a barrier to communication and the ability to provide support, and added considerable stress to the already challenging role of providing support to a loved one who is near the end of life. Three overarching themes were identified: Connectedness, Uncertainty, and Psychological Struggle. These qualitative themes were complemented by survey data about distance caregiving and the use of ICT in this context.

The overarching theme of Psychological struggle analysed how distance added a unique dimension to the experience of caregiving. Participants expressed how they felt they were living between "two dislocated worlds", whereby the world of their ill relative was perceived as opposed to their day-to-day life away (see Chapter 6). Carers found themselves needing to balance the dichotomy of their own world/life away from their relative, and the diseased world where the patient was. This shaped not only their experience of caregiving, but also affected their bereavement after their loved one had died, in the sense that participants felt "removed" from the diseased world of their relative after they had died, and often felt they needed more time in that world before returning to their own home after the death.

Douglas and colleagues (2016) looked specifically at distance caregiving, and identified not having to deal with the day to day reality of cancer caregiving as a benefit of distance caregiving. This is consistent with one of the findings from the present study, where participants talked about being able to step away, or felt that the distance offered them a 'buffer zone' whereby they were somehow temporarily shielded from the burden of caregiving. Despite these findings around positive aspects of distance caregiving, participants also spoke about feelings of guilt as a direct consequence of this. On the one hand, participants felt relieved that they did not have to live through the day-to-day experience of caregiving locally, and thus were able to enjoy leisure activities and somehow remove themselves from this difficult situation. On the other hand, they explained how, at the same time, this made them feel guilty. This inner conflict added to the psychological struggle that they felt by being divided between two different worlds, and contributed to the anguish that tinted this difficult experience.

Previous studies have explored the positive aspects of caregiving in palliative care, albeit *not* at a distance, identifying aspects such as "experiencing togetherness with others" and "sensing

togetherness with oneself" (Stoltz et al., 2006); a sense of closeness with their family and feeling respected by the healthcare staff (Mangan et al., 2003); and feeling closer to the patient and learning about personal strengths (Hudson, 2004). The theme of Connectedness identified in this dissertation is closely linked to such earlier findings; although connectedness was not identified as a positive aspect of distance caregiving as such, it was clear from all the interviews that the connection felt with their relative was a powerful and fulfilling emotional experience. In the field of cancer care research, one study reported two positive aspects of distance caregiving to a parent: some felt that communicating from a distance on the telephone had strengthened their relationship with their parent; one caregiver talked about how she felt that "not having to see" her ill mother every day somehow diminished the burden felt (Mazanec et al., 2011).

Results from the HADS instrument used in the survey indicated that participants who were current distance caregivers presented very high levels of depression and anxiety symptoms. Almost three quarters of participants obtained a score indicative of some level of depression, with over 40% being over the threshold (HADS indicating depression). In terms of anxiety, almost a third of participants were over the anxiety threshold, and only 5% of participants scored non-anxiety. The most recent study that analysed UK normative data (Breeman et al., 2015) reported that, for females in both the 45-59 and 50-54 age groups, the proportions of mild anxiety were around 18-20%, and the proportions of moderate/severe were around 19%. For males, the results for the same age groups were around 14% for both mild and moderate/severe (Breeman et al., 2015). The same study also indicated lower proportions of people with depressive symptoms: for the same age groups, around 10% of females scored mild depression, and around 8% scored moderate/severe depression. The results for males for the same age groups were similar, albeit slightly lower (Breeman et al., 2015). Other studies looking at anxiety and depression specifically in family carers of people with advanced cancer found a much higher prevalence of emotional distress in this population. A study that explored HADS scores in a sample of 96 primary caregivers for people with cancer in late palliative phase reported that the prevalence of anxiety was significantly higher than the norm for both genders, and for females in depression (Grov et al., 2005). A recent study reported that a third of palliative care cancer family caregivers obtained "definite case" scores of anxiety, while 15% obtained "suspicious case" scores (total sample n=72 relatives) (Götze et al., 2016). In terms of depression, the same study reported that 29% of participants were "definite cases", and a further 29% were "suspicious cases" (Götze et al., 2016). While much of the research using the HADS instrument in palliative care has focused on cancer, Hudson and colleagues conducted a study evaluating the psychological status of 301 family caregivers in palliative care (Hudson et al., 2011). This study reported that 44% of family caregivers presented probable anxiety and/or depression

according to HADS scores, and 40% scored over the cut-off of probable anxiety, while 20% scored over the cut-off for probable depression. The results from the studies that focus on family carers in palliative care are more in line with the findings of this doctorate.

Overall, the findings from the present study show how the experience of providing care from a distance is a challenging one that affects the emotional status of the family caregiver, and that the barrier of distance may play a role in this. While the emotional impact of family caregiving is widely acknowledged for those who provide care locally in palliative care, the same cannot be said about distance caregivers.

Further, the findings from the qualitative interviews were consistent with the HADS results from the survey, insofar as all participants talked about negative emotional symptoms, depression and anxiety issues, and stressed how the burden of distance actively contributed to increase these feelings.

How do distance caregivers in palliative care use ICT in their role as carers?

Most participants in this study used ICT to help manage the challenges that distance posed to caregiving. Chapters 5 and 6 have reported how the majority of participants found ICT a helpful resource in their role as distance caregivers. The findings from both the survey and the interviews were consistent, and the interviews added a rich and comprehensive perspective to the data from the survey.

Participants in the study used ICT as an aid to communication with the patient, the local carers and in some instances with the healthcare team, complementing traditional communication methods such as telephone calls, and sometimes substituting them when the geographical distance was significant. This study also showed the importance of having a variety of ways of communicating with a loved one when caring from a distance, and once again this was consistent in both datasets (quantitative and qualitative). Participants did not limit their use of ICT to a single device; instead, they used several gadgets in a complementary way: desktop computers, laptops, tablets and smart phones.

Videoconferencing particularly stood out during the interviews as a successful way to overcome the barrier of distance, and the survey results showed how videoconferencing was mostly used by those who lived at greater distances. Participants used proprietary platforms such as Skype® or FaceTime®, and those who used them had overwhelmingly positive experiences and spoke enthusiastically about this method of communication. Being able to see the patient on the screen in combination with using a mobile device such as a tablet or a smart phone seemed to provide an additional level

of closeness and intimacy to the distance relationship that could not be obtained solely through traditional telephone communication, by sharing the minutiae of day-to-day life and seemingly trivial yet significant activities. This was a fulfilling way of communicating that matched the experiences around Connectedness detailed in Chapter 6.

As indicated in Chapter 3, a large proportion of previous studies exploring the use of ICT in palliative care have focused on the role of videoconferencing technologies in enabling caregivers to participate in meetings or consultations with palliative care staff (Bensink et al., 2009; Bradford et al., 2012; Demiris et al., 2008, 2011, 2013; Parker Oliver & Demiris, 2010; Parker Oliver et al., 2010; Stern et al., 2012). All studies used videophones designed specifically for healthcare use. This poses two challenges. First, commonly used technology, especially smartphones and home computers, change at an extraordinarily fast rate, and the constant release of different models with improved features at affordable prices mean that many of these technologies often become rapidly obsolete. Thus, a particular technology used for videophone five or ten years ago may be completely outdated at present, making the findings less useful. Second, the present study showed how many distance caregivers and their relatives were already using their own commercial smart phones, computers or tablets for videoconferencing. This finding suggests that studies should focus on how people use their day-to-day devices, rather than be limited to devices that could only be used in a healthcare or research setting.

Being able to see their relative on the screen reassured distance caregivers and helped cope with the uncertainty in regards to how the patient “was really doing”, by giving carers a way to check their relative’s status. Uncertainty has been reported as a significant element of end of life care, both in cancer populations (McKechnie et al., 2007; Karlsson et al., 2014) and in non-cancer (Oishi & Murtagh, 2014). In these studies, uncertainty was identified throughout the different stages of cancer, from initial diagnosis to final days (McKechnie et al., 2007), and influenced different dimensions of the experience of cancer (Karlsson et al., 2014).

Mazanec’s PhD dissertation (2009) identified “dealing with uncertainty” as one of the sub-themes around distance caregiving to a parent with cancer. In her study, participants expressed uncertainty about how their parent “was really doing”, because they worried that they were not receiving accurate information from the patient or the local family carers (Mazanec, 2012). Although the present study used a different population (people near the end of life, regardless of the diagnosis, instead of limiting the inclusion to people with cancer), the findings around uncertainty in the present study were remarkably consistent with these previous findings. Uncertainty was also linked to travelling: participants struggled to know when it was necessary for them to travel to see their

relative in person. This increased the stress they were already experiencing, and was particularly acute in cases where the distance caregiver was in paid work, as travelling involved taking time off work at short notice, and often repeatedly.

Participants also used ICT to help cope with the uncertainty around their relative's condition, treatment and prognosis. Both quantitative and qualitative findings indicated that seeking information online was a widely used resource. The use of the internet for health information seeking has received considerable attention since the early 2000s. Recent publications have looked at how carers for someone with cancer have used the internet. Kinnane and Milne (2010) conducted a systematic review looking at the role of the internet in supporting and informing carers of people with cancer. The authors concluded that carers found accessing information online important, and that this was done in combination to other information sources such as healthcare professionals. The information could be sought for themselves or for the patient (Kinnane & Milne, 2010). Other studies included information seeking online as a part of the caregiving that relatives provide to patients with cancer, equating it to other tasks such as cooking or cleaning for the patient (Ginossar, 2008; Simon & Schramm, 2008). The findings from this doctorate are consistent with these studies, in so far as information seeking being carried out as a way of providing care. However these studies focused on the cancer setting, not on palliative care, which includes other conditions, and is not concerned with those with curable diseases. A recent systematic review looked at the effectiveness of ehealth interventions in palliative care (Capurro et al., 2014) and highlighted the small number of studies looking at the online information needs of family caregivers in palliative care: only five studies out of 17 included in the review. Finally, one study asked a small group of cancer distance caregivers (n=14) a few open-ended questions about distance caregiving, and reported briefly that distance caregivers might benefit from the use of ICT to provide care from a distance (Mazanec et al., 2011). However looking at the use of ICT was not an aim for this study and hence the data around this was very limited.

Although this PhD collected data from participants in nine geographically dispersed countries, almost three quarters of the survey respondents were British. The NHS announced a few years ago its aim of achieving a "Paperless NHS" by 2020 (National Information Board, 2014). One of the four objectives of this ambitious policy document was to empower carers. The UK Government committed to carers being able to access comprehensive, real-time data about the person that they care for, across all NHS services including General Practitioners and NHS Trusts, however the recommendations in this document are mainly strategic and hence do not provide a great level of detail on how this will be achieved. The findings from this doctorate showed that distance caregivers' views on ehealth are generally positive. Several participants in this study expressed

separately a very similar idea of what they would need as distance caregivers from healthcare services. First, they indicated that they would like to have access to an online system that was secure and regularly updated by healthcare professionals, and that they could access remotely. It was felt that this would enable them to receive more accurate and up-to-date information about their relative. Second, they wished that Wi-Fi was available in hospitals, so that they could keep on using ICT to keep in touch with their relative in the same way (videoconferencing, text messaging, emailing) that they did before the patient was not admitted. Third, they also indicated that they would find it very helpful to attend clinical appointments remotely via videoconferencing. These three needs identified in this study feed directly into the two overarching themes of Connectedness, by wanting to keep in touch with the patient and their healthcare professionals as much as possible, and Uncertainty, by wanting to access accurate and direct information about their relative's health.

Is distance caregiving different to local caregiving?

The vast majority of literature around family caregivers in palliative care focuses on family members who provide care locally or live in the same household as the patient. Many studies have reported on the kind of support that local family caregivers provide to a relative near the end of life. This has included a wide range of areas of care such as physical, emotional, social, financial, organisational and support in decision-making (Payne & Grande, 2013). Others have categorised these areas of care as: physical care, including personal care; symptom control, often involving more than one single symptom; emotional support; advocate and proxy decision-maker, including mediating in the communication with healthcare staff; practical and social support; and coordination of care, including planning and organising funeral arrangements (Stajduhar & Cohen, 2009).

Some studies have looked at the role of long distance caregivers, although not specifically in palliative care. Such studies reported that these caregivers provided emotional support (Roff et al., 2007; Bevan & Sparks, 2011; Carers UK, 2011); organised and coordinated on-site care arrangements, helped with housework (Bledsoe et al., 2010; Carers UK, 2011); transport (Bledsoe et al., 2010); provided legal support, help with paperwork and financial matters, and in many cases obtained power of attorney, especially in instances where there were not any local carers (Roff et al., 2007; Bledsoe et al., 2010; Carers UK, 2011).

The findings from this doctorate in regards to the support that distance caregivers provided were largely consistent with these studies, undoubtedly showing that distance caregivers supported their relative in a wide range of areas of care. Distance caregiving activities included emotional support, organisational support, coordinating from a distance the care provided locally, providing information and advice about medical decisions, and liaising and supervising healthcare professionals. The

connection that distance caregivers felt towards their relative often prompted an active role in their communication with local caregivers (usually siblings providing care locally) and wanting to be involved in the interaction with healthcare professionals. Distance caregivers also felt the need to “be there in person” with the patient and visited often, despite most of them finding it difficult or very difficult. Hence, their caregiving tasks were not limited to distance caregiving, but rather adapted to their location: if the carer was at a distance, they would be limited to the distance caregiving tasks aforementioned; when the carer visited in person, they would add to those the caregiving tasks traditionally associated to local caregivers, such as help with household chores, or personal care. In that sense, the distance mediated the kind of support that distance caregivers were able to provide, and participants provided as much care as they were able to, depending on whether they were physically with the patient or far from them. The overarching theme of Connectedness summarised this.

Overall, the findings from this dissertation showed that the care provided by distance caregivers did not differ much from the care provided by local caregivers. All the areas of care outlined by previous studies that looked specifically at palliative care family carers in the home (Stajduhar & Cohen, 2009; Payne & Grande, 2013) were present in this study. The main differences between local caregiving and distance caregiving were the way that the care was provided (from a distance, except when visiting in person), and the addition of further levels of stress associated to travelling, uncertainty and costs.

This study also explored the impact that distance caregiving has on the carer’s finances. Costs around travelling, accommodation, long distance telephone calls and international text messages added to the costs commonly associated with local caregiving, such as home improvements, aids, and paid carers. For those with limited financial means, the impact of the costs stemming from travelling and accommodation was particularly severe and contributed to stress levels. These findings were consistent with prior publications that addressed the costs of distance caregiving in general. Large surveys such as the Metlife study (2004) reported that long distance caregivers spent considerable amounts on a monthly basis on travelling arrangements and distance caregiving. The expenditure increased proportionally to the distance between the patient and the distance caregiver: the further away they lived, the higher the cost was. Another large USA-based survey reported a considerable difference between the monthly costs of local and distance caregivers (National Alliance for Caregiving, 2007). However, these surveys were USA-based and hence may not be applicable to other populations.

In relation to the impact on the financial status of these family caregivers, this doctorate also looked at the effect it had on the participants' ability to work full time. Both qualitative and quantitative data showed similar findings. The survey results indicated that over two thirds of the sample was at work. Findings from the qualitative interviews showed that many participants were able to keep their jobs while distance caregiving, while others indicated that they had had to leave their jobs because they wanted to have more flexibility to travel often or at short notice. In those cases where participants were working full time, the frequent travelling and the uncertainty associated with travelling had often a big impact on the carer's job. This issue has been looked at by previous studies. The Metlife survey (2004) reported a similar proportion of distance caregivers working full-time (around two thirds). In the UK, the 'Bridging the gap' report explored how caring at a distance is managed in the workplace, finding that almost half of the people surveyed said that distance caregiving had a negative effect on their work and that they needed support from their employers in terms of information about help available from the employer, awareness of carers' issues in the workplace, and flexible working patterns and leave arrangements (Carers UK, 2011).

The support that this sub-group of carers provides to their relative has been detailed throughout this dissertation, however this is in stark contrast to the resources available to them. There are not any government directives aimed at ensuring that distance caregivers receive the same support as local carers, or any support at all. On the contrary, most of the resources available for these carers are in the shape of online blogs, social media, and limited advice from a few charities.

The quantitative results from this study indicated that the majority of relatives in this study received care (in the case of current carers) or died (in the case of former carers) at home, and only around one in ten patients received care or died in a hospice. This finding echoes the current policy in England which, based on recent studies indicating that people's preferred place of death was home (Gomes & Higginson, 2006, 2008; Gomes et al., 2013) has advocated for patients to be able to die at home if they wish to. However, the assumption that home is always the preferred place of death has been challenged in recent years (Hoare et al., 2015; Pollock, 2015). The most recent data released by the Office of National Statistics (2016), based on the VOICES survey, indicated that according to family carers the places with the best overall quality of care during the last three months of life of the patient were, in this order, care homes, hospices and their own homes.

What are the needs of distance caregivers?

Palliative care services place great importance on family carers' needs, as discussed in the introductory chapters of this dissertation. While considerable work has been done around the needs of family carers in palliative care, this has been focused on *local* carers, mainly those who live at

home with the patient (Stajduhar & Cohen, 2009; Ewing et al., 2013b; Aoun et al., 2015a). The need for effective interventions targeted at addressing the unmet needs from family carers in palliative care has also been highlighted (Hudson et al., 2010a).

The FIN instrument was included as part of the questionnaire in this study. The findings showed that the most important needs for distance caregivers were around information. The two needs that participants scored as most important (having their questions answered honestly and being informed of changes in the patient's condition) were also two of the five needs that were met least often. This finding is especially relevant in light of England's policy framework Ambitions for Palliative and End of Life Care (National Palliative and End of Life Care Partnership, 2015), which outlines six ambitions for patients. The first of these ambitions explicitly mentions the patient's loved ones, and the importance of having accurate, honest and timely information:

Each person is seen as an individual. I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. (National Palliative and End of Life Care Partnership, 2015)

Similarly, the Department of Health recently published their response to the independent review of choice in end of life care, declaring a six-point commitment to the person approaching the end of their lives (Department of Health, 2016). The first point was that patients *"should be given the opportunity and support to have honest discussions about their needs and preferences for their physical, mental and spiritual wellbeing, so they can live well until they die"*, while the fifth point stated that patients will be supported to *"involve, to the extent that they wish, their family, carers and those important to them in discussions about, and the delivery of, the patient's care, and to give [the family] the opportunity to provide feedback about the patient's care"* (Department of Health, 2016). While this six point commitment explicitly refers to the patient, the combination of these two statements highlights the potential role of family caregivers. The findings of this PhD resonate with this policy and that of the Ambitions for Palliative and End of Life Care framework.

Further needs were identified upon the analysis of the data from the qualitative interviews. Participants talked about the importance of having accurate and timely information, which would help them cope with the uncertainty that caring from a distance entails. The results from the HADS questionnaire seem to indicate that the emotional impacts of distance caregiving, similarly to that of local caregiving, are considerable, and this is consistent with the need for emotional support that was discussed in some of the interviews. Further the feelings of guilt manifested by participants would arguably require emotional support. Finally, needs around bereavement were mentioned by those participants whose relative had already died.

This PhD study looked at the needs of distance caregivers in detail, using both quantitative methods (through the FIN instrument, as part of the survey), and qualitative methods (analysing the data from the interviews in regards to distance caregivers' needs). The data from the FIN scores were helpful to examine a wide range of 20 needs that carers might have, how these were rated in terms of importance, and how often these needs were met. However, in this way the data obtained was limited to only the 20 needs proposed by the FIN. By using qualitative interviews, participants were able to suggest needs that they had beyond the scope of the FIN, and also they gave great detail about their needs, and how they thought they could be addressed. In summary, this element of the PhD highlights the value of using mixed methods to address complex research questions.

7.2.2. Limitations and lessons learnt

This PhD had a number of limitations, and these are considered in this section. The section details challenges that arose, how these were addressed and the lessons that were learnt.

7.2.2.1. Recruitment strategy

As explained in Chapter 4 Methodology and Methods, the recruitment strategy initially set out for this study did not yield the anticipated number of participants and hence a new strategy was implemented.

Gatekeeping in palliative care

A growing number of studies have reported how palliative care patients and their families have a desire to participate in research (Gysels et al., 2008), and how not asking them to decide by themselves is undermining their autonomy (Terry et al., 2006; Sharkey, 2010). However, recruiting participants in palliative care research is often challenging. People near the end of life and their families are in a vulnerable situation, and there are a number of systems in place to ensure that their rights and well-being are protected. Research in palliative care often encounters what has been called *gatekeeping*, and difficulties when trying to access participants for research in palliative care are a common occurrence and have been widely reported (Sharkey, 2010; Kars et al., 2016). A recent systematic review (Kars et al., 2016) defined gatekeeping in palliative care as “*the process whereby actors involved in the research process prevent participation of eligible patients in clinical research*” (p. 546). The authors summarised the reasons for gatekeeping in the following categories: fear of burdening vulnerable patients and/or their relatives, difficulties around the disclosure of health status, hesitation about the quality or the importance of the study, and reluctant attitudes towards research expertise and logistics. In addition, the five main groups of people identified as gatekeepers were the healthcare professionals, research ethics committees, management, relatives and

researchers (Kars et al., 2015). Difficulties similar to those described by Kars and colleagues arose during this study, and these ultimately prompted a partial change in the recruitment strategy.

Following the approval by ethics committees, the recruitment of potential research participants through healthcare professionals was found to be very slow. Attendance at seminars and conferences was used to make and maintain connections with staff, by explaining the purpose of the study and helping them understand its relevance, and the potential benefits (such as identifying family carers that might not be local). While this seemed to speed up recruitment to some extent, it soon became apparent that other avenues of recruitment needed to be explored. This prompted a revision of the recruitment strategy that included making the questionnaire available online.

Using social media to recruit in palliative care

Some studies have advocated for alternative methods which could facilitate researcher's access to potential participants while still maintaining rigorous and comprehensive control to guarantee participants' well-being (Mitchell & Abernethy, 2005; Steinhauser et al., 2006; Walker & Read, 2011). The use of social media to recruit in healthcare research has been widely reported in recent years, and its use in palliative care research has also gained impetus in recent years (Taubert et al., 2014; Nwosu, 2015; Hopewell-Kelly et al., 2016). A recent publication outlined the opportunities of using social media in palliative care research (Casañas i Comabella & Wanat, 2014), including direct access to potential participants and not being limited to geographic proximity, thus enabling the researcher to reach a wider audience of potential participants.

Following careful consideration, a decision was made to make the questionnaire available online and use social media as an additional avenue for recruitment. This was supplementary to the face-to-face recruitment already in place, and recruitment via hospices and the community continued alongside this additional method. Ethical approval was obtained from REC and the University via a minor amendment.

Making the questionnaire available online and using social media to advertise the study were effective in yielding a larger number of participants. However, participants that were recruited via social media may have had different characteristics and experiences to those that were recruited through a clinical setting. Similarly, most of the participants in this study were White British females with high levels of education. While the higher levels of education is a consistent finding with previous research, it seems plausible that people with higher education levels are keener in research and are more IT literate, thus reflecting response bias.

The results from the HADS questionnaire indicated that a large proportion of participants presented anxiety and/or depression symptoms. However, the high levels of missing data might indicate that those who were experiencing emotional difficulties were more likely to complete the HADS. Response bias may affect these findings, and consequently they should be looked taking these limitations into account. Further, the use of social media to recruit part of the sample may bias the proportion of participants using ICT.

7.2.2.2. Small sample size

Despite the improvements made to the recruitment strategy, the final number of participants that took part in the survey was small. While 98 people took part in the survey, 19 returned questionnaires had to be excluded because of a high proportion of item non-response (where a participant had completed only part of the questionnaire), leaving the final number of participants at 79. This affected the quantitative analysis, which could only provide descriptive statistics: due to the small sample size, it was not possible to conduct sub-group analyses. In addition, this limits the confidence in the survey findings presented. This applies to all the quantitative results, including those around the HADS and FIN questionnaire results. Equally, comparisons between current and former carers could not be conducted as sub-group analysis was limited due to the small sample size.

Another limitation stemming from the small sample size was that results could not be split by group (disease groups, distance groups) for many of the variables. Further, specific non-cancer conditions such as MND or dementia could not be looked at separately.

Further, the use of a convenience sample precludes this study from extrapolating the results to the general population, as it is unknown how representative the sample was.

Nonetheless, even with these limitations the findings are important given the lack of research in this field: the present study is the first to explore the issue of distance caregiving in palliative care, and to provide any kind of data on the topic. This doctorate lays the foundation for further research on this overlooked group of carers. Further, this doctorate looked specifically at another area that needs attention: how these carers use ICT.

7.3. Conclusions

This PhD showed how distance caregiving in palliative care is a complex phenomenon that has received very little attention from researchers and policy makers.

This piece of research is the first to specifically address distance caregiving in palliative care, and hence has advanced the knowledge in this field by providing a comprehensive analysis of the characteristics, experiences and needs of this sub-group of family carers that were, until now, virtually invisible in palliative care. Their views and needs have been thoroughly examined, and the lack of support available to these carers in comparison to local carers has become apparent. In addition, this doctorate has explored how these carers use ICT, and their needs around this.

A mixed methods design combining a survey and qualitative interviews was used to explore this phenomenon in depth. The survey results were analysed using descriptive statistics. Data from the semi-structured qualitative interviews were thematically analysed using Framework Analysis. Findings from both methods of data collection were integrated after data analysis.

Seventy-nine people in nine different countries who were providing care from a distance to a relative near the end of life completed the survey questionnaire. Quantitative results showed that distance caregivers were commonly women of middle age in paid work and high levels of education providing care from a distance to a parent. Half of the respondents indicated that their relative had cancer. The vast majority of respondents reported that they had used ICT in their role as caregivers, and that they had found that helpful or very helpful.

Twenty-one of these respondents were interviewed. Three overarching themes were identified upon the analysis of the qualitative data. The first theme was Connectedness, and it showed how distance caregivers felt a deep emotional connection with their relative despite the geographical distance, which was perceived as a barrier in regards to the care that they would like to provide. This meant that they kept in touch with them very frequently, often using ICT, which was helpful to overcome the distance, and enabled them to share their day-to-day lives. The connectedness extended to other family members who were providing care locally, namely siblings, and the healthcare staff. The second theme was Uncertainty, and it looked at how distance added further uncertainty to the caregiving experience; this was especially felt by distance caregivers as their relatives' health deteriorated and death was imminent. The third overarching theme was Psychological Struggle, and this analysed the emotional conflicts that people often felt by feeling their lives were divided in two very different worlds: the healthy world and the sick world. Positive feelings around the distance such as being able to step away were reported, and these in turn generated feelings of guilt.

Integrating both quantitative and qualitative findings in the discussion provided a comprehensive exploration of distance caregiving in palliative care, by offering complementary insights on its different facets.

Several important implications for practice, policy and research stem from these findings, and will be discussed in the following section.

7.3.1. Implications for policy and practice

This study has shown that distance caregivers in palliative can provide significant support to their relatives near the end of life, but do not seem to benefit from as much recognition or support as local carers do, even in instances where they are the only family caregiver. It is hence of paramount importance that systems are put in place to ensure that healthcare staff are able to identify distance caregivers routinely, and to ensure that practice reflects current policy priorities (National Palliative and End of Life Care Partnership, 2015; Department of Health, 2016). Clinicians in all palliative care settings should ask their patients if they have a relative who lives far from them and who provides care from a distance. This should be done routinely and as part of the holistic care that is the main feature of palliative care. By doing this, services would ensure that these carers are identified. Further, this would facilitate the provision of appropriate support to this sub-group of family carers, which is in stark contrast to the support that local carers receive.

Participants in this study suggested three very specific ways in which they would like to use ICT to help them in their role as distance caregivers: being able to communicate with healthcare staff through email; having a secure online system regularly updated by healthcare professionals, in order to access accurate and up-to-date information about their relative; having Wi-Fi available in hospitals, so that they could keep on using ICT to keep in touch with their relative in the same way as when they were at home; and to attend clinical appointments remotely via videoconferencing. In terms of clinical implications, the two latter needs should be achievable. Hospitals already have Wi-Fi access for staff and students, and they should consider making this available for their patients. In regards to attending clinical appointments remotely, it seems reasonable to think that those patient and caregiver dyads that would wish to do so are the ones that already used that routinely, for instance, they often use Skype® on their smart phone to keep in touch with their adult children who live abroad. Clinicians should also consider allowing and encouraging patients who have distance caregivers to bring their usual device (tablet, smart phone) to the appointment with them, and use Skype® or FaceTime® during the consultation to add them to the interaction, and to ensure that they are accurately informed. This should be done exclusively when the patient wished to do so, and considering privacy and data security policies.

Service providers and clinicians should consider the possibility of piloting an online platform that carers (at a distance or local) could access remotely with up-to-date information about the patient. In considering this, issues around data protection, security and privacy should be carefully pondered.

Equally, the impact of such a system on the workload of healthcare staff should be examined. Most participants in this study thought that an online system would benefit them, but would also respect the priorities of busy clinical staff, by being less intrusive than telephone calls. However, it remains unclear if this would in fact be practicable and thus research is needed to explore feasibility.

Results from the survey around distance caregivers' needs corroborated recent policy documents around end of life care (National Palliative and End of Life Care Partnership, 2015; Department of Health, 2016), in regards to the importance of information needs about receiving timely and honest information. However, distance caregivers perceived these needs as being amongst the least met out of a list of 20 proposed needs (see Chapter 5). Policy makers should consider looking at improved ways of implementing these information goals for this sub-group of family carers.

Support for this particular population during the end of life period and during bereavement should be considered. This study has shown how sometimes distance caregivers felt that they were "in no-man's land" in regards to carer's support, because distance meant that they were not in the catchment area of the team that was providing care to their relative, and hence not suitable to receive support. Simultaneously, their local services and communities would not perceive them as family carers under strain, and as a result these carers would receive less support than local carers. This seemed to be especially acute during the bereavement phase.

The findings from this doctorate strongly back the recommendations suggested by the 'Bridging the gap' report (Carers UK, 2011), which proposed that employers should have a specific policy for carers, including distance caregivers, and ensure that the information is readily available in the workplace, and flexible arrangements for leave that would facilitate frequent or short notice travelling. Working remotely for periods of time should also be considered as an option for distance caregivers in the workforce.

7.3.2. Recommendations for future research

This thesis makes an important contribution to the field of family caregiving in palliative care and also generates a number of questions for future research, both for distance caregiving in general and for distance caregiving in palliative care in particular.

The findings from this study indicate the need for research to determine a unified definition of distance caregiving. This will help increase the visibility of this group of carers, who are often invisible in the clinical setting. The definition of distance caregivers should take into account the three core elements that define this phenomenon: the geographical distance (i.e. how many miles/kilometres the carer lives from the patient), the travel time it takes the carer to get the

patient, and the level of difficulty that visiting in person entails for the carer (see Figure 7.1).

Distance caregivers should be actively involved in the development of such a definition, which should involve different stakeholders through a Delphi process.

A large-scale survey is needed to gauge the figures of distance caregivers in palliative care. This should aim to identify whether there are any distance caregivers per patient, how many, and what their support and information needs are, which in turn would inform policy decision making. The vast majority of existing evidence focuses on the USA. Therefore, attention should be paid to the figures in Europe and other areas of the world, especially given current migration trends within Europe.

Further research with a larger, representative sample is also needed to explore whether distance caregivers in this setting use ICT in relation to the support they provide to their relative, how frequently, what kind of resources they use, the things that they find most helpful, and what devices they use. This research should focus on two aspects that have been key to this PhD. First, an online system whereby carers are able to access frequent updates about their loved one should be developed and piloted. Such online system should be jointly developed by clinicians, patients, family carers and web developers; the inclusion of the latter would ensure the system usability and accessibility. Second, the use of videoconferencing technologies as an aid to communication. This study showed how participants were already using proprietary platforms such as Skype® and FaceTime®. While these were evidently useful for participants in this study, they are owned by extremely successful corporations, which poses specific challenges in terms of data protection and security. Studies involving ethical boards need to address this, by exploring how people use these devices. Further, a study piloting the involvement of family caregivers via videoconferencing during clinical appointments should be conducted.

Finally, the views and attitudes of palliative care clinicians should be researched in regards to two specific topics. First, around the use of ICT to communicate with people under their care and their families, especially in regards to using videoconferencing devices during consultations and communicating with family carers through email. Second, the views and attitudes around distance caregivers in palliative care remain largely unknown, and these should be explored to ensure their engagement in potential interventions.

References

- Addington-Hall, J. (2007). Survey research. In Addington-Hall, J., Bruera, E., Higginson, I. J., & Payne, S. (Eds). *Research Methods in Palliative Care* (pp. 45-84). Oxford: Oxford University Press.
- Allert, G., Blasszauer, B., Boyd, K., & Callahan, D. (1996). The goals of medicine: setting new priorities. *The Hastings Center Report*, 26(6), S1.
- Alzheimer's Association. (2013). 2013 Alzheimer's disease facts and figures - Special report on distance caregiving. *Alzheimer's & dementia : the journal of the Alzheimer's Association*, 9(2), 208-245.
- Anderson, J. G. (2007). Social, ethical and legal barriers to e-health. *International journal of medical informatics*, 76(5), 480-483.
- Aoun, S., Deas, K., Toye, C., Ewing, G., Grande, G., & Stajduhar, K. (2015a). Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial. *Palliative medicine*, 29(6), 508-517.
- Aoun, S. M., Grande, G., Howting, D., Deas, K., Toye, C., Troeung, L., . . . Ewing, G. (2015b). The impact of the Carer Support Needs Assessment Tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One*, 10(4), e0123012.
- Benfield, L. E., & Beck, C. (2007). Reducing the distance in distance-caregiving by technology innovation. *Clinical interventions in aging*, 2(2).
- Bensink, M. E., Armfield, N. R., Pinkerton, R., Irving, H., Hallahan, A. R., Theodoros, D. G., . . . Wootton, R. (2009). Using videotelephony to support paediatric oncology-related palliative care in the home: From abandoned RCT to acceptability study. *Palliative Medicine*, 23(3), 228-237.
- Bevan, J. L., & Sparks, L. (2011). Communication in the context of long-distance family caregiving: An integrated review and practical applications. *Patient Education and Counseling*, 85(1), 26-30.
- Bledsoe, L. K., Moore, S. E., & Collins, W. L. (2010). Long distance caregiving: an evaluative review of the literature. *Ageing International*, 35(4), 293-310.
- Bradford, N., Young, J., Armfield, N. R., Bensink, M. E., Pedersen, L.-a., Herbert, A., & Smith, A. C. (2012). A pilot study of the effectiveness of home teleconsultations in paediatric palliative care. *Journal of telemedicine and telecare*, 18(8), 438-442.
- Breeman, S., Cotton, S., Fielding, S., & Jones, G. T. (2015). Normative data for the hospital anxiety and depression scale. *Quality of Life Research*, 24(2), 391-398.
- Cagle, J. G. (2008). *Informal caregivers of advanced cancer patients: The impact of geographic proximity on social support and bereavement adjustment*. VCU Thesis and Dissertations,

- Cagle, J. G., & Munn, J. C. (2012). Long-distance caregiving: a systematic review of the literature. *Journal of gerontological social work*, 55(8), 682-707.
- Callahan, D. (2000). Death and the research imperative. *The New England Journal of Medicine*, 342(9), 654-656.
- Candy, B., Jones, L., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database Syst Rev*, 15(6).
- Capurro, D., Ganzinger, M., Perez-Lu, J., & Knaup, P. (2014). Effectiveness of eHealth Interventions and Information Needs in Palliative Care: A Systematic Literature Review. *Journal of Medical Internet Research*, 16(3), e72.
- Carers UK. (2011). *Caring at a Distance: bridging the gap*. Retrieved from: <http://www.carersuk.org/newsroom/item/2191-caring-at-a-distance-bridging-the-gap>
- Carers UK. (2015). *Facts about carers*. Retrieved from: https://www.carersuk.org/images/Facts_about_Carers_2015.pdf
- Casañas i Comabella, C., & Wanat, M. (2014). Using social media in supportive and palliative care research. *BMJ supportive & palliative care*.
- Centeno, C. (1988). Historia y Desarrollo de los Cuidados Paliativos [History and development of Palliative Care]. In M. Gómez Sancho (Ed.), *Cuidados Paliativos e Intervención Psicosocial en enfermos de Cáncer [Palliative Care and Psychosocial Interventions in Cancer]*. Las Palmas (Spain): ICEPS.
- Centeno, C., Clark, D., Lynch, T., Rocafort, J., Flores, L. A., Greenwood, A., . . . De Lima, L. (2007). *EAPC Atlas of palliative care in Europe* (C. Centeno Ed.): IAHPCPress.
- Cohen, R., Leis, A. M., Kuhl, D., Charbonneau, C., Ritvo, P., & Ashbury, F. D. (2006). QOLTI-F: measuring family carer quality of life. *Palliative medicine*, 20(8), 755-767.
- Coleman, J., Olsen, S. J., Sauter, P. K., Baker, D., Hodgins, M. B., Stanfield, C., . . . Nolan, M. T. (2005). The effect of a Frequently Asked Questions module on a pancreatic cancer Web site patient/family chat room. *Cancer nursing*, 28(6), 460-468.
- Convey, V., Ede, J., & Sealey, T. (2008). How are the carers being cared for? A review of the literature. *European Journal of Palliative Care*, 15(4), 182-185.
- Cooper, D. L., Powe, B. D., & Smith, T. (2013). Social support provided by and strain experienced by African-American cancer caregivers. *Supportive Care in Cancer*, 1-7.
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research*. Los Angeles, CA: SAGE Publications.
- Critical Appraisal Skills Programme (CASP). (2014). *CASP Qualitative Checklist*. Retrieved from: http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf

- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of pain and symptom management*, 26(4), 922-953.
- Demiris, G., Oliver, D. P., & Courtney, K. (2006). Ethical considerations for the utilization of telehealth technologies in home and hospice care by the nursing profession. *Nurs Adm Q*, 30(1), 56-66.
- Demiris, G., Oliver, D. P., Courtney, K. L., & Day, M. (2007). Telehospice tools for caregivers: A pilot study. *Clinical Gerontologist*, 31(1), 43-57.
- Demiris, G., Oliver, D. P., Wittenberg-Lyles, E., & Washington, K. (2011). Use of videophones to deliver a cognitive-behavioural therapy to hospice caregivers. *Journal of telemedicine and telecare*, 17(3), 142-145.
- Demiris, G., Oliver, D. R., Hensel, B., Dickey, G., Rantz, M., & Skubic, M. (2008). Use of videophones for distant caregiving: an enriching experience for families and residents in long-term care. *Journal of gerontological nursing*, 34(7), 50-55.
- Demiris, G., Parker Oliver, D., Kruse, R. L., & Wittenberg-Lyles, E. (2013). Telehealth group interactions in the hospice setting: assessing technical quality across platforms. *Telemedicine Journal & E-Health*, 19(4), 235-240.
- Department of Health. (2008). *End of Life Care Strategy: Promoting high quality care for adults at the end of their life*. Retrieved from: <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>
- Department of Health. (2016). *Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf
- Dilorenzo, T. A., Bovbjerg, D. H., Montgomery, G. H., Valdimarsdottir, H., & Jacobsen, P. B. (1999). The application of a shortened version of the profile of mood states in a sample of breast cancer chemotherapy patients. *British Journal of Health Psychology*, 4(4), 315-325.
- Douglas, S. L., Mazanec, P., Lipson, A., & Leuchtag, M. (2016). Distance caregiving a family member with cancer: A review of the literature on distance caregiving and recommendations for future research. *World Journal of Clinical Oncology*, 7(2), 214-219.
- Drennan, J. (2003). Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *Journal of advanced nursing*, 42(1), 57-63.
- DuBenske, L. L., Gustafson, D. H., Namkoong, K., Hawkins, R. P., Atwood, A. K., Brown, R. L., . . . Cleary, J. F. (2014). CHES improves cancer caregivers' burden and mood: results of an eHealth RCT. *Health Psychology*, 33(10), 1261-1272.

- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286), 129-136.
- Evans, C. J., Stone, K. A., Manthorpe, J., & Higginson, I. J. (2013). *MRC guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care. Methods review 15*. London: National Institute for Health Research School for Social Care Research.
- Ewing, G., Brundle, C., Payne, S., Grande, G., & Home, N. A. f. H. a. (2013a). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *Journal of pain and symptom management*, 46(3), 395-405.
- Ewing, G., Grande, G., & Home, N. A. f. H. a. (2013b). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliative medicine*, 27(3), 244-256.
- Eysenbach, G. (2001). What is e-health? *Journal of medical Internet research*, 3(2).
- Farquhar, M. C., Ewing, G., & Booth, S. (2011). Using mixed methods to develop and evaluate complex interventions in palliative care research. *Palliative Medicine*, 25(8), 748-757.
- Farquhar, M., Preston, N., Evans, C. J., Grande, G., Short, V., Benalia, H., . . . Todd, o. b. o. M., Chris. (2013). Mixed methods research in the development and evaluation of complex interventions in palliative and end-of-life care: report on the MORECare consensus exercise. *Journal of Palliative Medicine*, 16(12), 1550-1560.
- Ferguson, T., & Frydman, G. (2004). The first generation of e-patients. *British Medical Journal*, 328(7449), 1148-1149.
- Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson (Eds.), *Circles of care : work and identity in women's lives* (pp. 35-62). Albany, N.Y.: State University of New York Press.
- Fridriksdottir, N., Sigurdardottir, V., & Gunnarsdottir, S. (2006). Important needs of families in acute and palliative care settings assessed with the family inventory of needs. *Palliative medicine*, 20(4), 425-432.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*, 13(1), 117.
- General Medical Council. (2010). *Treatment and care towards the end of life: good practice in decision making*. Retrieved from: http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life_English_1015.pdf 48902105.pdf
- Ginossar, T. (2008). Online participation: a content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. *Health Commun*, 23(1), 1-12.

- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*, 12(1), 7.
- Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *Bmj*, 332(7540), 515-521.
- Gomes, B., & Higginson, I. J. (2008). Where people die (1974—2030): past trends, future projections and implications for care. *Palliative medicine*, 22(1), 33-41.
- Götze, H., Brähler, E., Gansera, L., Schnabel, A., Gottschalk-Fleischer, A., & Köhler, N. (2016). Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European journal of cancer care*, 1-8.
- Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., . . . Todd, C. (2009). Supporting lay carers in end of life care: current gaps and future priorities. *Palliative medicine*, 23(4), 339-344.
- Grande, G. E., Farquhar, M. C., Barclay, S. I., & Todd, C. J. (2004). Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions. *Br J Gen Pract*, 54(507), 772-778.
- Green, J., & Thorogood, N. (2004). Analysing qualitative data. In J. Green & N. Thorogood (Eds.), *Qualitative methods for health research* (pp. 173-200). London: SAGE Publications Ltd.
- Green, J., & Thorogood, N. (2004). In-depth Interviews. In J. Green & N. Thorogood (Eds.), *Qualitative methods for health research* (pp. 79-106). London: SAGE Publications Ltd.
- Greenberg, A. (2015). First Case of Diphtheria in Spain Since 1986 After Parents Shun Vaccination. *Time*.
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational evaluation and policy analysis*, 11(3), 255-274.
- Grov, E. K., Dahl, A. A., Moum, T., & Fosså, S. D. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of oncology*, 16(7), 1185-1191.
- Gustafson, D. H., DuBenske, L. L., Namkoong, K., Hawkins, R., Chih, M. Y., Atwood, A. K., . . . Cleary, J. F. (2013). An eHealth system supporting palliative care for patients with non-small cell lung cancer: a randomized trial. *Cancer*, 119(9), 1744-1751.
- Gysels, M., Shipman, C., & Higginson, I. J. (2008). "I will do it if it will help others:" motivations among patients taking part in qualitative studies in palliative care. *Journal of pain and symptom management*, 35(4), 347-355.
- Hannon, B., O'Reilly, V., Bennett, K., Breen, K., & Lawlor, P. G. (2012). Meeting the family: Measuring effectiveness of family meetings in a specialist inpatient palliative care unit. *Palliative & supportive care*, 10(1), 43-49.

- Harding, R., & Higginson, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative medicine*, 17(1), 63-74.
- Harrigan, M., & Koerin, B. (2007). Long-distance caregiving: Personal realities and practice implications. *Reflections: Narratives of Professional Helping*, 13(2), 1-13.
- Health and Social Care Information Centre. (2015). *Personal Social Services Survey of Adult Carers in England 2014-15*. Retrieved from: <http://content.digital.nhs.uk/catalogue/PUB18423/per-soc-ser-sur-ad-car-eng-2014-15-rpt.pdf>
- Higginson, I. J., Evans, C. J., Grande, G., Preston, N., Morgan, M., McCrone, P., ... & Murray, S. A. (2013). Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC medicine*, 11(1), 111.
- Higginson, I. J., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *Journal of clinical epidemiology*, 63(5), 535-542.
- Hoare, S., Morris, Z. S., Kelly, M. P., Kuhn, I., & Barclay, S. (2015). Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS One*, 10(11), e0142723.
- Hollifield, J. F. (2004). The emerging migration state. *International migration review*, 38(3), 885-912.
- Hopewell-Kelly, N., Baillie, J., Sivell, S., Harrop, E., Bowyer, A., Taylor, S., . . . Byrne, A. (2016). Palliative care research centres move into social media: constructing a framework for ethical research, a consensus paper. *BMJ supportive & palliative care*, 0, 1-6.
- 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., & Payne, S. (2009). *Family carers in palliative care : a guide for health and social care professionals*. Oxford; New York: Oxford University Press.
- Hudson, P. L., Remedios, C., & Thomas, K. (2010a). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliat Care*, 9(1), 17.
- Hudson, P. L., Thomas, K., Trauer, T., Remedios, C., & Clarke, D. (2011). Psychological and social profile of family caregivers on commencement of palliative care. *Journal of pain and symptom management*, 41(3), 522-534.

- Hudson, P. L., Trauer, T., Graham, S., Grande, G., Ewing, G., Payne, S., . . . Thomas, K. (2010b). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative medicine*, 24(7), 656-668.
- Hwang, S. S., Chang, V. T., Alejandro, Y., Osenenko, P., Davis, C., Cogswell, J., ... & Kasimis, B. (2003). Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliative & supportive care*, 1(4), 319-329.
- Jadad, A. R., Rizo, C. A., & Enkin, M. W. (2003). I am a good patient, believe it or not. *BMJ: British Medical Journal*, 326(7402), 1293.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33(7), 14-26.
- Johnston, B. (2011). UK telehealth initiatives in palliative care: a review. *International journal of palliative nursing*, 17(6), 301-308.
- Joseph, A. E., & Hallman, B. C. (1998). Over the hill and far away: distance as a barrier to the provision of assistance to elderly relatives. *Social science & medicine*, 46(6), 631-639.
- Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. *Business horizons*, 53(1), 59-68.
- Karlsson, M., Friberg, F., Wallengren, C., & Öhlén, J. (2014). Meanings of existential uncertainty and certainty for people diagnosed with cancer and receiving palliative treatment: a life-world phenomenological study. *BMC Palliat Care*, 13, 28-28.
- Kars, M. C., van Thiel, G. J., van der Graaf, R., Moors, M., de Graeff, A., & van Delden, J. J. (2016). A systematic review of reasons for gatekeeping in palliative care research. *Palliative medicine*, 30(6), 533-548.
- Kellehear, A. (2009). Understanding the social and cultural dimensions of family caregiving. In P. Hudson & S. Payne (Eds.), *Family carers in palliative care : a guide for health and social care professionals*. Oxford: Oxford University Press.
- Kidd, L., Cayless, S., Johnston, B., & Wengstrom, Y. (2010). Telehealth in palliative care in the UK: a review of the evidence. *Journal of telemedicine and telecare*, 16(7), 394-402.
- Kilpatrick, M. G., Kristjanson, L. J., Tataryn, D. J., & Fraser, V. H. (1998). Information needs of husbands of women with breast cancer. *Oncology Nursing Forum*, 25(9), 1595-1601.
- Kinnane, N. A., & Milne, D. J. (2010). The role of the Internet in supporting and informing carers of people with cancer: a literature review. *Supportive Care in Cancer*, 18(9), 1123-1136.
- Klassen, A. C., Creswell, J., Plano Clark, V. L., Smith, K. C., & Meissner, H. I. (2012). Best practices in mixed methods for quality of life research. *Quality of Life Research*, 21(3), 377-380.

- Koerin, B. B., & Harrigan, M. P. (2003). PS I love you: Long-distance caregiving. *Journal of gerontological social work*, 40(1-2), 63-81.
- Kristjanson, L. J., & Aoun, S. (2004). Palliative care for families: remembering the hidden patients. *The Canadian Journal of Psychiatry*, 49(6), 359-365.
- Kristjanson, L. J., Atwood, J., & Degner, L. F. (1995). Validity and reliability of the family inventory of needs (FIN): measuring the care needs of families of advanced cancer patients. *Journal of nursing measurement*, 3(2), 109-126.
- Kruse, C. S., Karem, P., Shifflett, K., Vegi, L., Ravi, K., & Brooks, M. (2016). Evaluating barriers to adopting Telemedicine worldwide: A systematic review. *Journal of telemedicine and telecare*, 0(0), 1-9.
- Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 138-169). London: SAGE Publications Ltd.
- Letizia, M., Creech, S., Norton, E., Shanahan, M., & Hedges, L. (2004). Barriers to caregiver administration of pain medication in hospice care. *Journal of pain and symptom management*, 27(2), 114-124.
- Li, Q., & Loke, A. Y. (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.
- Lind, L., & Karlsson, D. (2004). A system for symptom assessment in advanced palliative home healthcare using digital pens. *Medical Informatics & the Internet in Medicine*, 29(3-4), 199-210.
- Lind, L., Karlsson, D., & Fridlund, B. (2008). Patients' use of digital pens for pain assessment in advanced palliative home healthcare. *International Journal of Medical Informatics*, 77(2), 129-136.
- Macmillan Cancer Care Support (2011). *More than a million. Understanding the UK's carers of people with cancer- a report by Ipsos Mori for Macmillan Cancer Support*. Retrieved from: https://www.macmillan.org.uk/_images/more-than-a-million_tcm9-300478.pdf
- Mangan, P. A., Taylor, K. L., Yabroff, K. R., Fleming, D. A., & Ingham, J. M. (2003). Caregiving near the end of life: unmet needs and potential solutions. *Palliative & supportive care*, 1(03), 247-259.
- Mansell, R. (2009). *The information society. Critical concepts in sociology*. London: Routledge.
- Masuda, Y. (1980). Emerging Information Society in Japan. In Y. Masuda (Ed.), *The Information Society as Post-Industrial Society* (pp. 3-22). Tokyo: Institute for the Information Society.

- Mazanec, P. (2009). *Distance Caregiving of a Parent with Advanced Cancer*. (PhD dissertation), Case Western Reserve University, Cleveland.
- Mazanec, P. (2012). Distance Caregiving a Parent With Cancer. *Seminars in Oncology Nursing*, 28(4), 271-278.
- Mazanec, P., Daly, B. J., Ferrell, B. R., & Prince-Paul, M. (2011). Lack of communication and control: experiences of distance caregivers of parents with advanced cancer. *Oncology nursing forum*, 38(3), 307-313.
- McCarthy, J. R., & Edwards, R. (2010). Care. In J. R. McCarthy & R. Edwards (Eds.), *Key concepts in family studies* (pp. 17-20). London: SAGE Publications Ltd.
- McKechnie, R., Macleod, R., & Keeling, S. (2007). Facing uncertainty: the lived experience of palliative care. *Palliative & supportive care*, 5(3), 255-264.
- Mickus, M. A., & Luz, C. C. (2002). Televisits: Sustaining long distance family relationships among institutionalized elders through technology. *Aging & mental health*, 6(4), 387-396.
- Mitchell, G. K., & Abernethy, A. P. (2005). A comparison of methodologies from two longitudinal community-based randomized controlled trials of similar interventions in palliative care: what worked and what did not? *Journal of Palliative Medicine*, 8(6), 1226-1237.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Open Medicine*, 3(2), 123-130.
- Moher, D., Schulz, K. F., & Altman, D. G. (2001). The CONSORT statement: revised recommendations for improving the quality of reports of parallel group randomized trials. *BMC medical research methodology*, 1(1).
- Monroe, B., & Oliviere, D. (2009). Communicating with family carers. In P. Hudson & S. Payne (Eds.), *Family Carers in Palliative Care: a Guide for Health and Social Care Professionals* (pp. 1-20). Oxford: Oxford University Press.
- National Alliance for Caregiving. (2004). *Miles Away: the MetLife Study of Long-distance Caregiving. Findings from a National Study by the National Alliance for Caregiving with Zogby International*. National Alliance for Caregiving. Washington, U.S.A.
- National Alliance for Caregiving. (2007). *Family caregivers - What they spend, what they sacrifice: Findings from a national study*. National Alliance for Caregiving. Washington, U.S.A.
- National Council for Palliative Care. (2013). *Who cares? Support for carers of people approaching the end of life*. Retrieved from http://www.ncpc.org.uk/sites/default/files/Who_Cares_Conference_Report.pdf

- National Information Board. (2014). *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A Framework for Action*. London, UK: National Information Board.
- National Palliative and End of Life Care Partnership. (2015). *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. London: National Palliative and End of Life Care Partnership.
- NHS England (2014). *Actions for End of Life Care: 2014-16*. Retrieved from: <https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>
- Nicholson, C. (2013). Palliative care on Twitter: who to follow to get started. *Int J Palliat Nurs*, 19(1), 6-7.
- Nik Jaafar, N. R., Selamat Din, S. H., Mohamed Saini, S., Ahmad, S. N. A., Midin, M., Sidi, H., . . . Baharudin, A. (2013). Clinical depression while caring for loved ones with breast cancer. *Comprehensive psychiatry*, 55, S52-S59.
- Nwosu, A. (2012). Palliative medicine and smartphones: an opportunity for innovation? *BMJ Supportive Palliative Care*, 2, 75-77.
- Nwosu, A. (2015). *Social media and palliative medicine: An opportunity for community and professional engagement*. Retrieved from: <https://eapcnet.wordpress.com/2015/08/17/social-media-and-palliative-medicine-an-opportunity-for-community-and-professional-engagement/>
- O'Cathain, A., Murphy, E., & Nicholl, J. (2007). Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. *BMC health services research*, 7(1), 85.
- O'Reilly, T. (2005). *Web 2.0: Compact Definition?* Retrieved from: <http://radar.oreilly.com/2005/10/web-20-compact-definition.html>
- Office of National Statistics (2011). *2011 Census questionnaire*. Retrieved from: <https://www.ons.gov.uk/file?uri=/census/censustransformationprogramme/consultations/the2021censusinitialviewoncontentforenglandandwales/2011censusquestionnaireenglandh1.pdf>
- Office of National Statistics. (2016). *National Survey of Bereaved People (VOICES): England, 2015. Statistical release*. London: Office of National Statistics.
- Oishi, A., & Murtagh, F. E. (2014). The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals. *Palliative medicine*, 28(9), 1081-1098.

- Park, B., Kim, S. Y., Shin, J.-Y., Sanson-Fisher, R. W., Shin, D. W., Cho, J., & Park, J.-H. (2013). Prevalence and predictors of anxiety and depression among family caregivers of cancer patients: a nationwide survey of patient–family caregiver dyads in Korea. *Age*, 54(1), 60-63.
- Parker, M. W., Church, W., Toseland, R. W., & Berkman, B. (2006). Caregiving at a distance. In *Handbook on aging and social work* (pp. 391-406). New York, U.S.A.: Haworth Press New York.
- Parker Oliver, D., & Demiris, G. (2010). Comparing face-to-face and telehealth-mediated delivery of a psychoeducational intervention: a case comparison study in hospice. *Telemedicine Journal & E-Health*, 16(6), 751-753.
- Parker Oliver, D., Demiris, G., Wittenberg-Lyles, E., Porock, D., Collier, J., & Arthur, A. (2010). Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *American Journal of Hospice & Palliative Medicine*, 27(7), 465-473.
- Patients and Information Directorate. (2013). *Transforming Participation in Health and Care: 'The NHS belongs to us all'*. Retrieved from <https://www.england.nhs.uk/2013/09/trans-part/>
- Payne, S. (2007). Qualitative methods of data collection and analysis. In Addington-Hall, J., Bruera, E., Higginson, I. J., & Payne, S. (Eds). *Research Methods in Palliative Care* (pp. 139-161). Oxford: Oxford University Press.
- Payne, S. (2010a). EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. *European Journal of Palliative Care*, 17(5), 238-245.
- Payne, S. (2010b). EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 2. *European Journal of Palliative Care*, 17(6), 286-290.
- Payne, S., & Grande, G. (2013). Towards better support for family carers: A richer understanding. *Palliative medicine*, 27(7), 579-580.
- Payne, S., & Hudson, P. (2008). Assessing the family and caregivers. In D. Walsh (Ed.), *Palliative medicine* (pp. 320-325). Philadelphia: Saunders Elsevier.
- Payne, S., & Morbey, H. (2013). *Supporting family carers: report on the evidence of how to work with and support family carers to inform the work of the Commission into the future of hospice care*. Help the Hospices. London.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The gerontologist*, 30(5), 583-594.
- Pereira, S. M., Fonseca, A. M., & Carvalho, A. S. (2012). Burnout in nurses working in Portuguese palliative care teams: a mixed methods study. *International journal of palliative nursing*, 18(8), 373-381.

- Pollock, K. (2015). Is home always the best and preferred place of death? *BMJ: British Medical Journal*, 351, 1-3.
- Powell, J., Darvell, M., & Gray, J. (2003). The doctor, the patient and the world-wide web: how the internet is changing healthcare. *Journal of the Royal Society of Medicine*, 96(2), 74-76.
- Radbruch, L., & 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), 278-289.
- Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. *The qualitative researcher's companion*, 573(2002), 305-329.
- Roff, L. L., Martin, S. S., Jennings, L. K., Parker, M. W., & Harmon, D. K. (2007). Long Distance Parental Caregivers' Experiences with Siblings A Qualitative Study. *Qualitative Social Work*, 6(3), 315-334.
- Sampson, E. L., Thuné-Boyle, I., Kukkastenvehmas, R., Jones, L., Tookman, A., King, M., & Blanchard, M. R. (2008). Palliative care in advanced dementia; A mixed methods approach for the development of a complex intervention. *BMC Palliative Care*, 7(1), 8.
- Saunders, C. (2005). Foreword. In D. Doyle, G. Hanks, N. Cherny, & K. Calman (Eds.), *Oxford Textbook of Palliative Medicine* (3rd ed.). Oxford: Oxford University Press.
- Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of pain and symptom management*, 24(2), 91-96.
- Sharkey, K., Savulescu, J., Aranda, S., & Schofield, P. (2010). Clinician gate-keeping in clinical research is not ethically defensible: an analysis. *Journal of Medical Ethics*, 36(6), 363-366.
- Simon, C., & Schramm, S. (2008). Cancer and the computerized family: towards a clinical ethics of "indirect" Internet use. *Medicine, Health Care and Philosophy*, 11(3), 337-341.
- Skilbeck, J. K., Payne, S. A., Ingleton, M. C., Nolan, M., Carey, I., & Hanson, A. (2005). An exploration of family carers' experience of respite services in one specialist palliative care unit. *Palliative Medicine*, 19(8), 610-618.
- Smith, A. K., Sudore, R. L., & Pérez-Stable, E. J. (2009). Palliative care for Latino patients and their families: whenever we prayed, she wept. *Jama*, 301(10), 1047-1057.
- Soothill, K., Morris, S., Harman, J., Francis, B., Thomas, C., & McIlmurray, M. B. (2001). Informal carers of cancer patients: what are their unmet psychosocial needs? *Health & social care in the community*, 9(6), 464-475.
- Spencer, L., Ritchie, J., Ormston, R., O'Connor, W., & Barnard, M. (2014). Analysis: Principles and Practices. In J. Ritchie, J. Lewis, C. McNaughton Nicholls, & R. Ormston (Eds.), *Qualitative Research Practice* (pp.269-294). London: Sage Publications Ltd.

- Stajduhar, K., & Cohen, R. (2009). Family caregiving in the home. In P. Hudson & S. Payne (Eds.), *Family carers in palliative care* (pp. 149-168). Oxford: Oxford University Press.
- Stajduhar, K. I., Funk, L., & Outcalt, L. (2013). Family caregiver learning—how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets. *Palliative medicine*, 27(7), 657-664.
- Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., . . . Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative medicine*, 20(8), 745-754.
- Stern, A., Valaitis, R., Weir, R., & Jadad, A. R. (2012). Use of home telehealth in palliative cancer care: a case study. *Journal of telemedicine and telecare*, 18(5), 297-300.
- Stoltz, P., Willman, A., & Udén, G. (2006). The meaning of support as narrated by family carers who care for a senior relative at home. *Qualitative Health Research*, 16(5), 594-610.
- Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: prospects and challenges for health psychology. *Health Psychology*, 23(2), 119-125.
- Taubert, M., Watts, G., Boland, J., & Radbruch, L. (2014). Palliative social media. *BMJ supportive & palliative care*, 4(1), 13-18.
- Terry, W., Olson, L., Ravenscroft, P., Wilss, L., & Boulton-Lewis, G. (2006). Hospice patients' views on research in palliative care. *Internal medicine journal*, 36(7), 406-413.
- Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., . . . Goldsmith, C. H. (2010). A tutorial on pilot studies: the what, why and how. *BMC medical research methodology*, 10(1).
- The Economist Intelligence Unit. (2015). *The 2015 Quality of Death Index. Ranking palliative care across the world*. Retrieved from: <http://eol.law.dal.ca/wp-content/uploads/2017/05/2015-EIU-Quality-of-Death-Index-Oct-29-FINAL.pdf>
- The Guardian. (2015, 22 February). 'We are not anti-science': mothers defend right to not vaccinate children. *The Guardian*.
- Tosh, W. (2013). It can be tough for families when patients choose to die at home. *BMJ: British Medical Journal (Online)*, 346.
- Tronto, J. C. (1993). *Moral boundaries : a political argument for an ethic of care*. New York: Routledge.
- Ventura, A. D., Burney, S., Brooker, J., Fletcher, J., & Ricciardelli, L. (2013). Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers. *Palliative medicine*, 28(5), 391-402.
- Vincent, A., Herman, J., Schulick, R., Hruban, R. H., & Goggins, M. (2011). Pancreatic cancer. *The Lancet*, 378(9791), 607-620.

- Vishwanath, A., & Scamurra, S. D. (2007). Barriers to the adoption of electronic health records: using concept mapping to develop a comprehensive empirical model. *Health Informatics Journal*, 13(2), 119-134.
- Wagner, D. L. (1997). *Caring across the miles: Findings of a survey of long-distance caregivers. Final Report for The National Council on the Aging*. Washington, DC: National Council on the Aging.
- Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed-methods study. *Health & Social Work*, 32(3), 197-206.
- Walker, S., & Read, S. (2011). Accessing vulnerable research populations: an experience with gatekeepers of ethical approval. *International journal of palliative nursing*, 17(1), 14-18.
- Weitzner, M. A., Jacobsen, P. B., Wagner, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index–Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8(1-2), 55-63.
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal medicine*, 176(3), 372-379.
- World Health Organisation. (2004). *The solid facts. Palliative care*. Retrieved from: http://www.euro.who.int/_data/assets/pdf_file/0003/98418/E82931.pdf
- World Health Organisation. (2014). *WHO Definition of Palliative Care*. Retrieved from: <http://www.who.int/cancer/palliative/definition/en/>
- World Health Organisation. (2015). *Health topics: eHealth*. Retrieved from: <http://www.who.int/topics/ehealth/en/>
- World Health Organization. (2016). *Global diffusion of eHealth: making universal health coverage achievable: report of the third global survey on eHealth*. Geneva: World Health Organisation.
- Worldwide Palliative Care Alliance. (2014). *Global Atlas of Palliative Care at the End of Life*. Retrieved from: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf
- Zarit, S., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. New York, U.S.A.: New York University Press.
- Zarit, S. H., & Edwards, A. B. (1999). Family caregiving: research and clinical intervention. In R. T. Woods (Ed.), *Psychological problems of ageing : assessment, treatment and care* (pp. 153-193). Chichester; New York: Wiley.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, 67(6), 361-370.

Appendix 2.1. Search strategy

1. carer*.mp.
2. caregiver*.mp.
3. caring.mp.
4. 1 or 2 or 3
5. distance.mp.
6. long-distance.mp.
7. 5 or 6
8. 4 and 7
9. (car* adj3 distance).mp.
10. 8 or 9
11. palliative care.mp.
12. end of life.mp.
13. advanced cancer.mp.
14. advanced dementia.mp.
15. advanced alzheimer*.mp.
16. advanced disease.mp.
17. advanced illness.mp.
18. advanced MND.mp.
19. advanced motor neuron disease.mp.
20. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21. 10 and 20

Appendix 2.2. Characteristics of the articles included in the literature review about distance caregiving

Author/s, Date, Country	Sample	Setting	Study design	Publication type
Cagle 2008 USA	106 informal caregivers of patients with cancer, including 25 long-distance caregivers. Eight long-distance caregivers completed the post-death survey.	13 palliative care hospices	Survey	Doctoral dissertation
Smith et al. 2009 USA	Female patient with leukaemia.	University hospital	Single case	Peer-reviewed journal
Mazanec 2009 USA	80 adult children who provided care to a parent with advanced cancer, 40 of which were at a distance.	Cancer Centre outpatient ambulatory	Survey and structured telephone	Doctoral dissertation
Mazanec et al. 2011 USA	Sub-set of the sample above: 14 participants.	As above	Qualitative structured interviews	Peer-reviewed journal

Appendix 3.1. Search Strategy

- 1 palliative care.mp.
- 2 end of life.mp.
- 3 supportive care.mp.
- 4 terminal.mp.
- 5 advanced.mp.
- 6 hospice*.mp.
- 7 1 or 2 or 3 or 4 or 5 or 6
- 8 ehealth.mp.
- 9 e-health.mp.
- 10 electronic health.mp.
- 11 telehealth.mp.
- 12 (Information and Communication Technolog*).mp.
- 13 ICT.mp.
- 14 mhealth.mp.
- 15 m-health.mp.
- 16 mobile health.mp.
- 17 Short Message Service*.mp.
- 18 SMS.mp.
- 19 text messag*.mp.
- 20 smartphone*.mp.
- 21 mobile phone*.mp.
- 22 mobile telephone*.mp.
- 23 cell* phone*.mp.
- 24 cell* telephone*.mp.

- 25 computer based.mp.
- 26 ehospice.mp.
- 27 e-hospice.mp.
- 28 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or
25 or 26 or 27
- 29 carer*.mp.
- 30 caregiver*.mp.
- 31 children*.mp.
- 32 parent*.mp.
- 33 famil*.mp.
- 34 relative*.mp.
- 35 29 or 30 or 31 or 32 or 33 or 34
- 36 7 and 28 and 35

Appendix 3.2. Quality appraisal tools

Sample of CASP Qualitative Checklist (Critical Appraisal Skills Programme (CASP), 2014):



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting
There will not be time in the small groups to answer them all in detail!

©CASP This work is licensed under the Creative Commons Attribution - NonCommercial-ShareAlike 3.0 Unported License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/3.0/> www.casp-uk.net

Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?



Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

CONSORT checklist (Moher et al., 2001):



CONSORT 2010 checklist of information to include when reporting a randomised trial

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a randomised trial in the title	
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale	
	2b	Specific objectives or hypotheses	
Methods			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	
Participants	4a	Eligibility criteria for participants	
	4b	Settings and locations where the data were collected	
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	
	6b	Any changes to trial outcomes after the trial commenced, with reasons	

Sample size	7a	How sample size was determined	
	7b	When applicable, explanation of any interim analyses and stopping guidelines	
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	
	13b	For each group, losses and exclusions after randomisation, together with reasons	
Recruitment	14a	Dates defining the periods of recruitment and follow-up	
	14b	Why the trial ended or was stopped	
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	

Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	
Discussion			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	
Other information			
Registration	23	Registration number and name of trial registry	
Protocol	24	Where the full trial protocol can be accessed, if available	
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	

Pilot study checklist (Thabane et al., 2010):

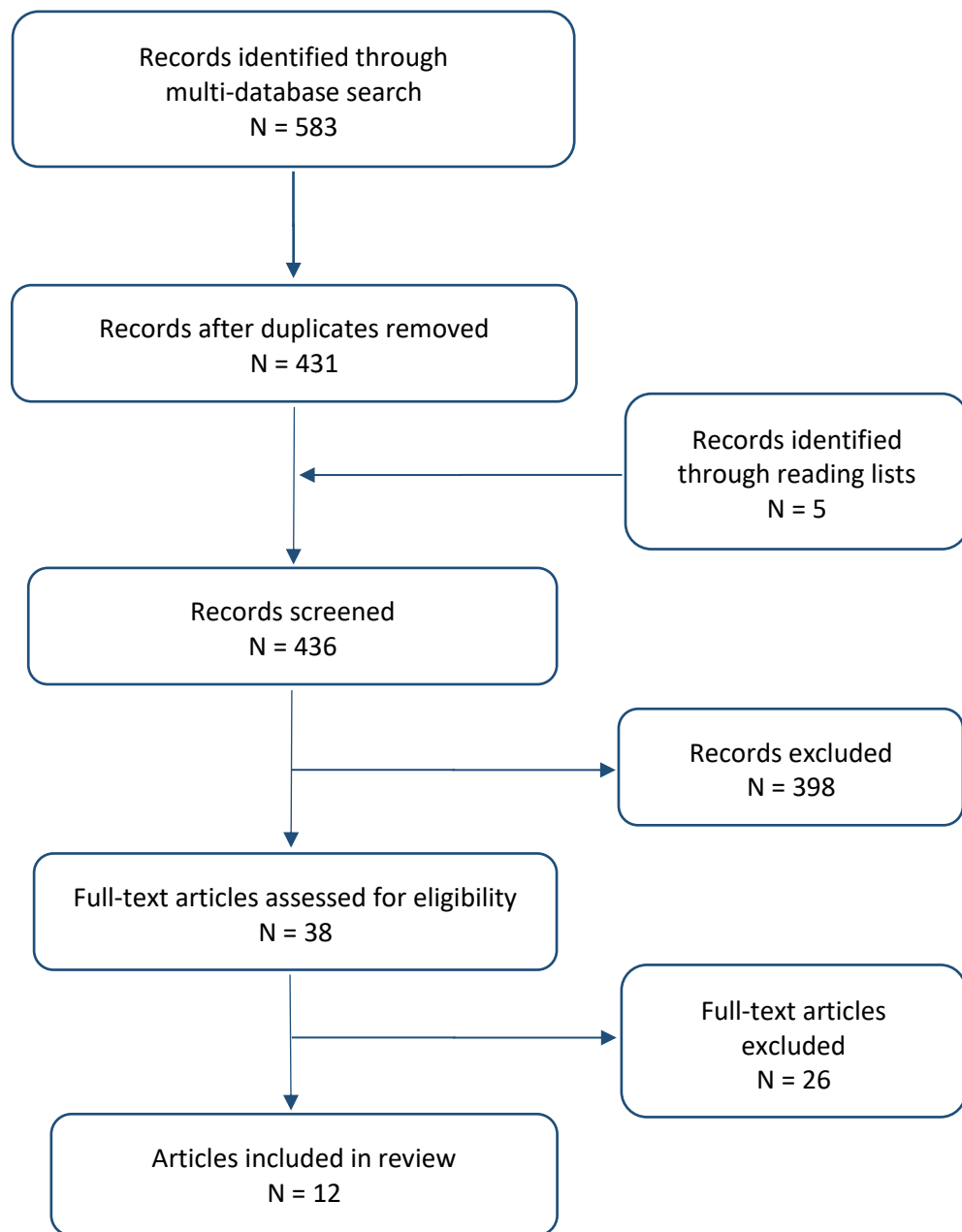
Pilot Study - Checklist: Items to include when reporting a pilot study			
PAPER SECTION	Item	Descriptor	Reported on Page #
TITLE <i>and</i> ABSTRACT	1	Does the title or abstract indicate that the study is a "pilot"?	
INTRODUCTION			
Background	2	Scientific background for the main study and explanation of rationale for assessing feasibility through piloting	
METHODS			
Participants and setting	3	• Eligibility criteria for participants in the pilot study (these should be the same as in the main study -- if different, state the differences) • The settings and locations where the data were collected	
Interventions	4	Provide precise details of the interventions intended for each group and how and when they were actually administered (if applicable) -- state clearly if any aspects of the intervention are assessed for feasibility	
Objectives	5	• Specific scientific objectives and hypotheses for the main study • Specific feasibility objectives	

Outcomes	6	• Clearly defined primary and secondary outcome measures for the main study • Clearly define the feasibility outcomes and how they were operationalized -- these should include key elements such as recruitment rates, consent rates, completion rates, variance estimates, etc
Sample size	7	Describe how sample size was determined • In general for a pilot of a phase III trial, there is no need for a formal sample size calculation. However, confidence interval approach may be used to calculate and justify the sample size based on key feasibility objective(s).
Feasibility Criteria	8	Clearly describe the criteria for assessing success of feasibility -- these should be based on the feasibility objectives
Statistical Methods	9	Describe the statistical methods for the analysis of primary and secondary feasibility outcomes
Ethical Aspects	10	• State whether the study received research ethics approval • State how informed consent was handled -- given the feasibility nature of the study
RESULTS		
Participant flow	11	Flow of participants through each stage (a flow-chart is strongly recommended). • Describe protocol deviations from pilot study as planned, together with reasons

		• State the number of exclusions at each stage and reasons for exclusions
Recruitment	12	Report the dates defining the periods of recruitment and follow-up
Baseline data	13	Report the baseline demographic and clinical characteristics of the participants
Outcomes and estimation	14	For each primary and secondary feasibility outcome, report the point estimate of effect and its precision (<i>e.g.</i> , 95% confidence interval [CI]) -- if applicable
DISCUSSION		
Interpretation	15	Interpretation of the results should focus on feasibility, taking into account • the stated criteria for success of feasibility; • study hypotheses, sources of potential bias or imprecision -- given the feasibility nature of the study • the dangers associated with multiplicity of analyses and outcomes
Generalizability	16	Generalizability (external validity) of the feasibility. State clearly what modifications in the design of the main study (if any) would be necessary to make it feasible
Overall evidence of feasibility	17	General interpretation of the results in the context of current evidence of feasibility • Focus should be on feasibility

Appendix 3.3. Flowchart of inclusion process

PRISMA (Moher et al., 2009) flowchart of inclusion process in the literature review:



Appendix 3.4. Characteristics of the articles included in the literature review about ehealth

Author/s, Date, Country	Sample	Setting	Intervention	Design	Findings	Quality appraisal (tool used)
Bensink et al., 2009 Brisbane (Australia)	11 families	Palliative care home support paediatric oncology service.	Home telehealth program (HTP), to provide specialist consultations via videoconference	Feasibility study	Videotelephone support from nurses was an acceptable way to provide support to paediatric oncology-related palliative care families, as part of the routine care provided by the medical team.	Low quality (adapted CONSORT checklist)
Bradford et al., 2012 Australia Same study as above	14 family caregivers	As above	As above n=6 in intervention group (HTP) n=6 in control group (standard care)	Pilot study - prospective exploratory cohort	No differences in quality of life between family caregivers in the intervention group (those who used HTP) and those in the control group (standard care)	Medium quality (adapted CONSORT checklist)
Coleman et al., 2005 USA	600 social media posts (undetermined number of family caregivers)	Pancreatic cancer general hospital website	Online chat room for patients with pancreatic cancer and their families	Descriptive- comparative mixed methods	Themes identified in the posts: information seeking, giving, or both; support seeking, giving or both; and reporting status or death. Information was around treatments, nutrition, prognosis, end of life care, cost of care, symptoms and support. Most people who posted on the chat room were daughters of patients. Questions about fatigue decreased by 3-fold after the addition of an FAQ module on the website.	Medium-high quality (CASP qualitative checklist)

Author/s, Date, Country	Sample	Setting	Intervention	Design	Findings	Quality appraisal (tool used)
Demiris et al., 2007 USA	12 senior family caregivers	One rural hospice and one urban hospice	Participants used a bespoke videotelephone to communicate with hospice staff	Pilot study	Following the intervention, participants showed a reduction in anxiety scores ($p=0.05$). Family caregivers valued the visual feedback during videoconferences and videophones were perceived as easy to use.	Medium-high quality (adapted CONSORT checklist)
Demiris et al., 2011 USA	42 hospice family caregivers	Hospices	Problem-solving therapy (PST) delivered through videoconference (total of 3 calls)	Single arm feasibility study (design not specified in publication)	Significant reduction of anxiety ($p=0.04$) after having received the intervention. Participants generally satisfied with videophone intervention.	Low quality (adapted CONSORT checklist)
Demiris et al., 2013 USA Same study Parker Oliver et al., 2010	19 caregivers	Two rural hospices	Participants were able to join hospice team meetings remotely using a bespoke videotelephone system	Qualitative interviews to assess caregivers' impressions of videoconferences with hospice teams	Participants found the intervention positive and useful overall. Technical issues were categorised as: audio delay, challenges with being able to hear all the people in the room through the videotelephone, overall video quality, and ease of use of the videotelephone.	Medium quality (CASP qualitative checklist)

Author/s, Date, Country	Sample	Setting	Intervention	Design	Findings	Quality appraisal (tool used)
DuBenske et al., 2014 USA	285 advanced NSCLC patient-caregiver dyads	4 cancer centres	n=144 used password-protected website <i>Coping with Lung Cancer</i> from CHESS (Comprehensive Health Enhancement Support System) n=141 used internet (training on how to use the internet + list of recommended sites about lung cancer)	Randomised trial assessing the effect on mood, burden and carers' disruptiveness	Caregivers in the CHESS arm showed significantly lower levels of burden and negative mood.	High quality (CONSORT RCT checklist)
Gustafson et al., 2013 USA Same study as above	As above	As above	As above	Randomised trial exploring the use of CHESS by patient-caregiver dyads, its effect on survival rates and on patients' symptom control	73% of caregivers in the intervention arm used CHESS at least once, and 51.6% used CHESS 5 times or more Caregivers in the CHESS arm reported lower patient physical symptom distress at 4 and 6 months Exploratory analysis indicated there were no differences between survival curves between groups	Medium-high (CONSORT RCT checklist)
Lind et al., 2008 Sweden	12 palliative care cancer patients 4 spouses	Palliative care home service	Patient and caregiver dyads used a digital pen diary to assess the patient's level of pain 3 times per day until pain was controlled	Case study with cross-case content analysis	Caregivers played a role in reminding the patients to carry out their pain assessment, and helped them solve technical problems The use of the digital pen diary increased contact with healthcare providers and led to a sense of increased security and calmness	Medium-high quality (CASP qualitative checklist)

Author/s, Date, Country	Sample	Setting	Intervention	Design	Findings	Quality appraisal (tool used)
Parker Oliver & Demiris, 2010 USA Same study as Demiris et al., 2011	2 caregivers	Two rural hospices	n=1 Problem-solving intervention online (videophone) n=1 Same, face-to-face	Case comparison study	Both caregivers were satisfied with the intervention The participant who received the intervention via videophone attributed 15% of the success to the video image	Low quality (CASP qualitative checklist)
Parker Oliver et al., 2010 USA	Historical comparison group = 41 caregivers Intervention group = 32 caregivers	Two rural hospices	Historical comparison group = standard care. Intervention group = standard care + videotelephone to join hospice team meetings remotely.	Pilot study with mixed methods two phase design	No significant differences between comparison and intervention groups Intervention was deemed feasible as caregivers were able to use the videotelephone technology.	Low quality (adapted CONSORT checklist)
Stern et al., 2012 Canada	5 advanced cancer patient-caregiver dyads 7 bereaved family caregivers	Community-based palliative care service	Specialist nurses (tele-nurses) available 24/7 via videophone, with optional remote monitoring of blood pressure, blood oxygen levels, and heart, lung and abdominal sounds	Mixed methods with a focus on qualitative methods	Caregivers felt that the use of the system would have been more beneficial if it had been introduced earlier in the disease trajectory While the system was perceived as easy to use, there were technical problems in a third of the video calls with the tele-nurse	Medium-low quality (CASP qualitative checklist)

Appendix 4.1. Letters of ethics approval from FREC



Appendix 4.2. Letters of ethics approval from NRES


Health Research Authority

NRES Committee South Central - Oxford C
Bristol REC Centre
Level 3, Block B
Whitefriars Building
Levin's Mead
Bristol
BS1 2NT
Telephone: 01173421387

6th March 2014

Ms Carolina Casañas i Comabella
Department of Clinical Health Care
Faculty of Health and Life Sciences, Oxford Brookes University
Jack Straws Lane
OX3 0FL

Dear Ms Casañas i Comabella,

Study title: Carers at a distance in palliative care: a mixed-methods study exploring the role of ehealth.
REC reference: 13/SC/0528
IRAS project ID: 125475

Thank you for your letter of 27th February 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 30 October 2013.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		27 February 2014
Participant Information Sheet	2.3	11 February 2014
Questionnaire: Recruited through community	4.3	24 February 2014
Questionnaire: Recruited through patients	4.3	24 February 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Advertisement	3	12 August 2013
Covering Letter	11/09/13	11 September 2013
Covering Letter		27 February 2014
Evidence of insurance or indemnity	S. Wilkinson	11 July 2013
Interview Schedules/Topic Guides	2	03 July 2013

A Research Ethics Committee established by the Health Research Authority

Health Research Authority

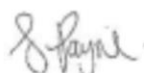
Investigator CV	C. Casanals Comabella	
Letter from Sponsor	H. Abbott	22 August 2013
Letter of invitation to participant	2.1	06 August 2013
Letter of invitation to participant	2.1	06 August 2013
Other: CV-Supervisor	Prof Boulton	
Other: CV-Supervisor	Prof Watson	
Other: CV-Supervisor	Dr Wee	
Other: Letter from funder	M. Boulton	03 September 2013
Other: Oxford Brookes University Ethics Approval letter	H. Abbott	22 August 2013
Other: Oxford Brookes University Ethics Approval Form	H. Abbott	22 August 2013
Participant Consent Form	2	27 June 2013
Participant Information Sheet	2.3	11 February 2014
Protocol	2.2	02 September 2013
Questionnaire: HAD Scale	Validated	
Questionnaire: FIN	Validated	
Questionnaire: Recruited through community	4.3	24 February 2014
Questionnaire: Recruited through patients	4.3	24 February 2014
REC application	5/09/13	05 September 2013
Referees or other scientific critique report	H. Abbott	22 August 2013
Summary/Synopsis	2	14 August 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/SC/0528

Please quote this number on all correspondence

Yours sincerely,



Sarah Payne
Research Ethics Committee Assistant
E-mail: nrescommittee.southcentral-oxford@nhs.net

Copy to: Ms Hazel Abbott,

Appendix 4.3. Poster advertising the study



ARE YOU CARING AT A DISTANCE?

Do you have a relative who is near the end of life?

Does he or she live away from you?

If so, we would like to hear from you. You are invited to participate in a study exploring the views and experiences of relatives who provide care and support from a distance.



An opportunity to have your say

If you would like to know more, please contact:

Carolina Casañas i Comabella
Department of Clinical Health Care
Oxford Brookes University
OX3 0FL

Email: 12090237@brookes.ac.uk

Tel: 01865 482 814

This study has been approved by the NHS Research Ethics Committee
[insert ref number]

Appendix 4.4. Leaflets for professionals and for patients

Leaflet for healthcare professionals:



Carers at a distance in palliative care: exploring the role of ehealth

NRES reference: 13/SC/0528

This is a PhD study being conducted at the Department of Clinical Health Care, Oxford Brookes University.

Principal Investigator: Carolina Casañas i Comabella

Tel: 01865 482 814

Email: 12090237@brookes.ac.uk

PhD supervisors: Prof Bee Wee

Prof Eila Watson

Prof Mary Boulton

You are being asked to recruit participants for this PhD study

What are the objectives of the study?

- Describe the characteristics of people that care at a distance in palliative care.
- Explore what are the needs and experiences of people that care at a distance in palliative care.
- Explore the benefits and risks that the use of ehealth by these carers may have on the care they provide to people near the end of life.

Who do I need to recruit for this study?

In this study, we will only look at carers at a distance (as opposed to local carers). When we say “at a distance”, we mean **relatives who are restricted in how often they can visit because they do not live nearby.**

What is ehealth?

eHealth is the use of the internet for health purposes.

Inclusion criteria:

- Male or female, aged 18 or above.
- A relative who is providing any kind of meaningful support, as identified by the patient, to a person near the end of life.
- A relative who is identified by the patient as a relative who is involved in caring, albeit at a distance. **Distance caregiving might include regular phone calls or visits, organisational support, financial help, and so on.**
- Able to understand and sign informed consent.

What do I need to do to recruit participants for this study?

During your regular home visit or follow-up telephone call, inform the patient about the study.



Ask the patient:

Do you have a relative who, despite not living locally to you, provides support to you in any way? This may be by calling you regularly, or visiting when they can, or helping you with organising care or financial support.



If the patient says that they have indeed a carer at a distance, please ask the patient to ask that person if they would be willing receive a letter with information about the study. The study consists of a short postal survey, and, if they are interested, one telephone interview.



When you get the contact details of the relative, please send them to me.



Please make it clear to the patient that the person that would participate in the study is the distance carer, not the patient.

The only task for the patient is to tell you who the distance carer/s is/are and give you their contact details, so that I can send them the information about the study.

Thank you very much for your help

DO YOU HAVE A RELATIVE WHO LIVES AT A DISTANCE FROM YOU?

OXFORD
BROOKES
UNIVERSITY

Do you have a relative who lives away from you, but still provides support that makes a difference? This could be by calling you often, or visiting whenever they can, or providing financial support.

If you have a relative who provides any kind of support from a distance, we would like to ask them to take part in a study, by means of completing a short postal survey.



If you would like to know more, please contact:

Carolina Casañas i Comabella
Department of Clinical Health
Care
Oxford Brookes University
OX3 0FL

Tel: 01865 482 814

Email: 12090237@brookes.ac.uk

**This study has been approved
by the NHS Research Ethics
Committee.**

An opportunity to contribute to research

You are being asked to pass on the contact details of a relative who provides care to you from a distance.

What is the purpose of the study?

The purpose of this study is to better understand the views and experiences of people who are providing care from a distance to a relative who is unwell, and to understand any needs they may have.

What do I need to do to help?

I am interested in relatives who provide *any kind* of support to you, but who do not live nearby.

For the purposes of this study, we have defined “carer” as a **relative who provides *any kind* of significant care. This is not necessarily hands-on care. Care can also mean calling you regularly over the phone, offering emotional support, dealing with health care professionals, organising private or charity care, providing financial support, and so on.**

When we say “at a distance”, we mean relatives who are restricted in how often they can visit because they do not live nearby.

What will happen to my relative if they decide to take part?

Taking part in this research is **entirely voluntary**. If your relative decides to take part, they will be asked to complete a

short postal questionnaire and send it back to Oxford Brookes University in a FREEPOST self-addressed envelope.

Your relative may also be asked if they would like to take part in an informal telephone interview so we can understand their experiences in more detail. **All data will be kept entirely confidential.**

What should I do if my relative wants to take part?

If your relative wants to take part in the study, or if they simply want to learn more about it, there are different ways to contact me:

- a) You may give the contact details of your relative (with their permission) to the nurse that gave you this leaflet.
- b) You or your relative may contact me at:

Carolina Casañas i Comabella
Department of Clinical Health Care
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
OX3 0FL

Tel: +44 (0)1865 482 814
Email: 12090237@brookes.ac.uk

Thank you very much for your help

Appendix 4.5. Invitation letters for potential participants

Letter for potential participants recruited via the patient:

[Brookes headed paper]

Carolina Casañas i Comabella
Department of Clinical Health Care
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
Oxford OX3 0FL
Email: 12090237@brookes.ac.uk
Tel: 01865 482 814

[Date]

[Name]

[Adress Line 1]

[Adress Line 2]

[Postcode]

Dear **[Name]**,

Re: Carers at a distance in palliative care: postal survey.

We are contacting you because your relative has indicated that you might be willing to participate in our research study by receiving the survey enclosed, and has provided your postal address. We are inviting individuals who are providing any kind of care and support at a distance to a relative with a life-limiting illness.

We know that caring for someone with a life-limiting illness may be a challenging experience. However, very little is known about relatives who live away from the patient and cannot provide hands-on, day-to-day care. The purpose of our research is to explore the needs and experiences of people who are caring at a distance for a relative who is seriously ill. To do this, we would like to invite you to complete the enclosed questionnaire to tell us about your experience. When you have completed your questionnaire, please return it in the prepaid envelope.

In the second stage of this research project, we would like to conduct some telephone interviews to explore these issues in more depth. If you think you might be interested and would like to find out more, please complete your contact details in section E in the questionnaire and fill in and sign the enclosed Interview Consent Form before you send both back. If you are happy to complete the enclosed questionnaire but you do not want to be contacted about the next stage of the research, please leave the contact details blank and ignore the consent form.

Taking part in this study is entirely voluntary. The research team will not be passed any information about you. Your questionnaire responses will be confidential, unless you are interested in taking part in stage 2 of the research and provide your contact details on the questionnaire. If you do provide contact details, the information you provide on the questionnaire will be treated in the strictest confidence.

You are free to withdraw at any time, without giving a reason, until such time as the data are analysed. This would not affect the standard of care that you or your relative receive.

This study has been approved by the NHS Research Ethics Committee Oxford **[Name of Oxford's committee] [Reference number]**. This research project is part of my PhD, which I am conducting at the Department of Clinical Health Care, at Oxford Brookes University, under the supervision of Prof Mary Boulton, Prof Eila Watson and Prof Bee Wee.

Before you decide if you want to take part in the study, please read the Participant Information Sheet enclosed. If you have any questions about taking part in this research, please do not hesitate to contact me (details above).

Thank you very much for considering taking part in this study.

Yours sincerely,

[Ink signature]

Carolina Casañas i Comabella

Letter for potential participants recruited via the community (as the reader will notice, only the first paragraph was modified slightly from the letter for people recruited via the patient):

[Brookes headed paper]

Carolina Casañas i Comabella
Department of Clinical Health Care
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
Oxford OX3 0FL
Email: 12090237@brookes.ac.uk
Tel: 01865 482 814

[Date]

[Name]

[Adress Line 1]

[Adress Line 2]

[Postcode]

Dear **[Name]**,

Re: Carers at a distance in palliative care: postal survey.

Thank you for having expressed an interest in taking part in this research project. We are inviting individuals who are providing any kind of care and support at a distance to a relative with a life-limiting illness.

We know that caring for someone with a life-limiting illness may be a challenging experience. However, very little is known about relatives who live away from the patient and cannot provide hands-on, day-to-day care. The purpose of our research is to explore the needs and experiences of people who are caring at a distance for a relative who is seriously ill. To do this, we would like to invite you to complete the enclosed questionnaire to tell us about your experience. When you have completed your questionnaire, please return it in the prepaid envelope.

In the second stage of this research project, we would like to conduct some telephone interviews to explore these issues in more depth. If you think you might be interested and would like to find out

more, please complete your contact details in section E in the questionnaire and fill in and sign the enclosed Interview Consent Form before you send both back. If you are happy to complete the enclosed questionnaire but you do not want to be contacted about the next stage of the research, please leave the contact details blank and ignore the consent form.

Taking part in this study is entirely voluntary. The research team will not be passed any information about you. Your questionnaire responses will be confidential, unless you are interested in taking part in stage 2 of the research and provide your contact details on the questionnaire. If you do provide contact details, the information you provide on the questionnaire will be treated in the strictest confidence.

You are free to withdraw at any time, without giving a reason, until such time as the data are analysed. This would not affect the standard of care that you or your relative receive.

This study has been approved by the NHS Research Ethics Committee Oxford **[Name of Oxford's committee] [Reference number]**. This research project is part of my PhD, which I am conducting at the Department of Clinical Health Care, at Oxford Brookes University, under the supervision of Prof Mary Boulton, Prof Eila Watson and Prof Bee Wee.

Before you decide if you want to take part in the study, please read the Participant Information Sheet enclosed. If you have any questions about taking part in this research, please do not hesitate to contact me (details above).

Thank you very much for considering taking part in this study.

Yours sincerely,

[Ink signature]

Carolina Casañas i Comabella

Appendix 4.6. The paper version of the questionnaire

Unique study ID:	
------------------	--

**OXFORD
BROOKES
UNIVERSITY**

Caring from a distance

Thank you for agreeing to receive this survey. Your relative who is currently ill has suggested that you might be willing to contribute to this study. We would like to ask about your experience, which will help us to better understand the experience of providing support to a loved one from a distance.

Enclosed are a participant information sheet and a FREEPOST envelope. Please read the participant information sheet before completing the questionnaire. Participation in this research study is voluntary. If you do decide to participate in the postal survey, please complete and return the questionnaire. By doing this, you consent for us to use your responses in our research. It will take you about 20 minutes to complete the questionnaire.

After I have received these survey responses, I will be conducting some telephone interviews. If you are interested in finding out more about this and possibly taking part, please fill in your contact details in section F. Even if you send back your details, you are under no obligation to take part. If you are not interested, please leave that section blank when you return your questionnaire.

Please read each question carefully. There are no right or wrong answers to these questions. If you decide there are any questions you would rather not answer, please just go to the next question.

All the information you give will be treated as strictly confidential

If you have any questions about any aspect of completing the questionnaire please contact the Chief Investigator of this study:

Carolina Casañas i Comabella
Telephone: 01865 482814
Email: 12090237@brookes.ac.uk

Thank you very much for your help

Carers at a distance in palliative care
Questionnaire – participants recruited through patient
Version 4.4 – 29 April 2014

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

SECTION A: CAREGIVING

These questions are about your relationship with the person who is ill and your role as a relative who provides support from a distance.

A1	When was your relative diagnosed with his/her illness? <i>Please write in the month & year if you know this</i>	Month: Year:	
A2	What is your relative's illness?		
A3	How is the patient related to you? <i>Please tick all that apply</i>	☐ ¹ ☐ ² ☐ ³ ☐ ⁴ ☐ ⁵ ☐ ⁶ ☐ ⁰	My father My mother My son My daughter My brother My sister Other <i>Please specify</i>
A4	Where is your relative now?	☐ ¹ ☐ ² ☐ ³ ☐ ⁴ ☐ ⁰	Their own home Hospice Hospital Nursing or residential home Other <i>Please specify</i>
A5	For how long have you been providing support, in any way, for your relative?	☐ ¹ ☐ ² ☐ ³ ☐ ⁴ ☐ ⁵	Three months or less Between 3 months to 1 year Between 1 and 2 years Between 2 and 5 years Over 5 years
A6	Which of the following activities does your relative need support with? <i>Please tick all that apply</i>	☐ ¹ ☐ ² ☐ ³ ☐ ⁴ ☐ ⁵ ☐ ⁶	Shopping, collecting prescriptions, other errands Transport (i.e. they need someone to drive them or go with them in the bus) on trips/to appointments Cooking, cleaning, laundry, gardening or other household jobs Getting advice and information about their disease, support available Making phone calls, writing letters or emails, filling in forms Talking to others on their behalf (e.g. healthcare staff, social worker)

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

		☐ ⁷ Taking their medication ☐ ⁸ Home maintenance, repairs, adaptations ☐ ⁹ Managing finances ☐ ¹⁰ Personal care (e.g. washing, dressing, toileting or feeding) ☐ ¹¹ My relative cannot be left alone and needs someone to be with him or her all the time ☐ ⁰ Other <i>Please specify</i>
A7	Who is involved <u>locally</u> in the day to day care of your relative? <i>Please tick all that apply</i>	☐ ¹ His or her spouse/partner ☐ ² His or her son/s ☐ ³ His or her daughter/s ☐ ⁴ His or her father ☐ ⁵ His or her mother ☐ ⁶ His or her brother/s ☐ ⁷ His or her sister/s ☐ ⁸ Friend/s ☐ ⁹ Neighbour/s ☐ ¹⁰ A paid carer (not NHS) ☐ ¹¹ No one is involved in local care <i>please go to A8</i> ☐ ⁰ Other <i>Please specify</i>
A8	What is the relationship of the local carer(s) to you? <i>Please tick all that apply</i>	☐ ¹ The person who provides care locally is my relative <i>Please specify</i> ☐ ² The person who provides care locally is a friend of my relative ☐ ³ The person who provides care locally is someone I employ ☐ ⁴ I do not have a relationship with the person who provides care locally ☐ ⁰ Other <i>Please specify</i>
A9	How far do you live from your relative?	☐ ¹ Ten miles or less ☐ ² Between 11 and 30 miles ☐ ³ Between 31 and 50 miles ☐ ⁴ Between 51 and 100 miles ☐ ⁵ More than 100 miles within the UK ☐ ⁶ I live in a different country – <i>less than 1 day travel</i> ☐ ⁷ I live in a different country – <i>more than 1 day travel</i>
A10	How long does it take you to get to your relative?	☐ ¹ Less than 1 hour ☐ ² One to 3 hours ☐ ³ Half a day ☐ ⁴ More than half a day

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

A11	How easy is it for you to visit your relative?	☐ ¹ Very easy ☐ ² Easy ☐ ³ Difficult ☐ ⁴ Very difficult
A12	How often did you visit your relative in person <i>in the last 6 months</i> ?	☐ ¹ I was not able to visit in the last 6 months ☐ ² Less than once a month ☐ ³ At least once a month ☐ ⁰ More often than once a month <i>please specify</i>
A13	How do you keep in touch <i>with your relative</i> ? <i>Please tick all that apply</i>	☐ ¹ Phone call ☐ ² Phone text ☐ ³ Email ☐ ⁴ Skype ☐ ⁵ Visiting in person ☐ ⁰ Other <i>Please specify</i>
A14	How do you communicate <i>with the medical team</i> that looks after your relative? <i>Please tick all that apply</i>	☐ ¹ I have not communicated with the medical team ☐ ² Phone call ☐ ³ Phone text ☐ ⁴ Email ☐ ⁵ Skype ☐ ⁶ Meeting them directly ☐ ⁰ Other <i>Please specify</i>
A15	What kind of support do you give to your relative from a distance? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>	

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

A16	Do you have any concerns about the support you provide to your relative? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>	☐ ¹ ☐ ²	I do not have any concerns about the support that I provide to my relative My main concern is:
A17	What do you find most helpful currently <i>for you as a carer at a distance</i> (e.g. being able to talk with your relative, having information about their illness...)? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>		

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

SECTION B: ABOUT YOUR USE OF THE INTERNET FOR HEALTH PURPOSES

These questions are about how you use the internet for health purposes. Firstly there are questions around how you use the internet for your own health, and then in your role as a carer. Please ignore any technical terms that you might not be familiar with, and answer the questions *even if you do not use the internet*.

B1	Do you have regular access to a computer?	☐ ¹ Yes ☐ ² No
B2	Have you ever used the internet?	☐ ¹ Yes ☐ ² No → Please go to B15
B3	Do you have an email address?	☐ ¹ Yes ☐ ² No
B4	Have you ever used the internet in relation to <u>your own health</u> ?	☐ ¹ Every day ☐ ² At least once a week ☐ ³ At least once a month ☐ ⁴ Only occasionally (less than once a month) ☐ ⁵ No, never → Please go to B9
B5	When you have used the internet in relation to <u>your own health</u> , what have you used it for? <i>Please tick all that apply</i>	☐ ¹ To find out information about health for yourself ☐ ² To find out about practical aspects (for instance, how to contact a hospital or how to get there) ☐ ³ To book an appointment with doctor/nurse for yourself ☐ ⁴ To order repeat prescriptions ☐ ⁵ To share experiences of my own health with other people (for instance, an online support forum) ☐ ⁰ Other <i>Please specify</i>
B6	Overall, how helpful have you found using the internet in relation to <u>your own health</u> ?	☐ ¹ Very helpful ☐ ² Somewhat helpful ☐ ³ Not very helpful ☐ ⁴ Not at all helpful ☐ ⁵ I don't know
B7	What advantages, if any, have you found when using the internet in relation to <u>your own health</u> ? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>	

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

B8	What disadvantages, if any, have you found when using the internet in relation to <u>your own health</u>? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>		
B9	Have you ever used the internet <u>in your role as a carer</u>?	☐ ¹ Every day ☐ ² At least once a week ☐ ³ At least once a month ☐ ⁴ Only occasionally (less than once a month) ☐ ⁵ No, never → Please go to B15	
B10	When you have used the internet <u>in your role as a carer</u>, what have you used it for? <i>Please tick all that apply</i>	☐ ¹ To find out information about the health problem of my relative ☐ ² To find out about practical aspects for my relative (for instance, how can he or she contact a hospital or how can he or she get there) ☐ ³ To book an appointment with doctor/nurse for my relative ☐ ⁴ To find out information about how to provide support ☐ ⁵ To share my experiences <i>as a carer</i> with other people (for instance, an online forum for carers) ☐ ⁰ Other <i>Please specify</i>	
B11	Overall, how helpful have you found using the internet <u>in your role as a carer</u>, in relation to <u>your relative's needs</u>?	☐ ¹ Very helpful ☐ ² Somewhat helpful ☐ ³ Not very helpful ☐ ⁴ Not at all helpful ☐ ⁵ I don't know	
B12	What advantages, if any, have you found when using the internet <u>in your role as a carer</u>, in relation to <u>your relative's needs</u>? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>		
B13	What disadvantages, if any, have you found when using the internet <u>in your role as a carer</u>, in relation to <u>your relative's needs</u>? <i>Please explain in the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>		

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

B14	When you have used the internet for health purposes (either for you or in relation to your relative), what kind of device did you use? <i>Please tick all that apply</i>	☐¹ Desktop computer ☐² Laptop ☐³ Tablet (e.g. an iPad or a Samsung tablet) ☐⁴ Smart phone ☐⁵ I don't know/can't remember ☐⁰ Other <i>Please specify</i>
B15	What are the main barriers that prevent you from using the internet to access health resources? <i>Please tick all that apply</i>	☐¹ I do not know how to use computers or smart phones ☐² I do not have a computer or smart phone ☐³ I do not know how to go online (i.e. how to use the internet) ☐⁴ The cost of access (e.g. the cost of a broadband connection, or the cost of a computer) ☐⁵ Limited access to broadband ☐⁶ I don't know ☐⁰ Other <i>Please specify</i>
B16	Are there any websites that you have found particularly useful <i>in your role as a carer</i>? Please indicate the names and explain why they were useful in the box provided. <i>Please write down the name, even if you cannot remember the complete web address.</i>	

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

SECTION C: YOUR FEELINGS OVER THE LAST WEEK

Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the **past week**. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

C1 I feel tense or wound up: <table border="1"> <tr><td>☐³ Most of the time</td></tr> <tr><td>☐² A lot of the time</td></tr> <tr><td>☐¹ From time to time, occasionally</td></tr> <tr><td>☐⁰ Not at all</td></tr> </table>	☐ ³ Most of the time	☐ ² A lot of the time	☐ ¹ From time to time, occasionally	☐ ⁰ Not at all	C8 I feel as if I am slowed down: <table border="1"> <tr><td>☐³ Nearly all the time</td></tr> <tr><td>☐² Very often</td></tr> <tr><td>☐¹ Sometimes</td></tr> <tr><td>☐⁰ Not at all</td></tr> </table>	☐ ³ Nearly all the time	☐ ² Very often	☐ ¹ Sometimes	☐ ⁰ Not at all
☐ ³ Most of the time									
☐ ² A lot of the time									
☐ ¹ From time to time, occasionally									
☐ ⁰ Not at all									
☐ ³ Nearly all the time									
☐ ² Very often									
☐ ¹ Sometimes									
☐ ⁰ Not at all									
C2 I still enjoy the things I used to enjoy: <table border="1"> <tr><td>☐⁰ Definitely as much</td></tr> <tr><td>☐¹ Not quite so much</td></tr> <tr><td>☐² Only a little</td></tr> <tr><td>☐³ Hardly at all</td></tr> </table>	☐ ⁰ Definitely as much	☐ ¹ Not quite so much	☐ ² Only a little	☐ ³ Hardly at all	C9 I get a sort of frightened feeling like "butterflies" in the stomach: <table border="1"> <tr><td>☐⁰ Not at all</td></tr> <tr><td>☐¹ Occasionally</td></tr> <tr><td>☐² Quite often</td></tr> <tr><td>☐³ Very often</td></tr> </table>	☐ ⁰ Not at all	☐ ¹ Occasionally	☐ ² Quite often	☐ ³ Very often
☐ ⁰ Definitely as much									
☐ ¹ Not quite so much									
☐ ² Only a little									
☐ ³ Hardly at all									
☐ ⁰ Not at all									
☐ ¹ Occasionally									
☐ ² Quite often									
☐ ³ Very often									
C3 I get a sort of frightened feeling as if something awful is about to happen: <table border="1"> <tr><td>☐³ Very definitely and quite badly</td></tr> <tr><td>☐² Yes, but not too badly</td></tr> <tr><td>☐¹ A little, but it doesn't worry me</td></tr> <tr><td>☐⁰ Not at all</td></tr> </table>	☐ ³ Very definitely and quite badly	☐ ² Yes, but not too badly	☐ ¹ A little, but it doesn't worry me	☐ ⁰ Not at all	C10 I have lost interest in my appearance: <table border="1"> <tr><td>☐³ Definitely</td></tr> <tr><td>☐² I don't take as much care as I should</td></tr> <tr><td>☐¹ I may not take quite as much care</td></tr> <tr><td>☐⁰ I take just as much care as ever</td></tr> </table>	☐ ³ Definitely	☐ ² I don't take as much care as I should	☐ ¹ I may not take quite as much care	☐ ⁰ I take just as much care as ever
☐ ³ Very definitely and quite badly									
☐ ² Yes, but not too badly									
☐ ¹ A little, but it doesn't worry me									
☐ ⁰ Not at all									
☐ ³ Definitely									
☐ ² I don't take as much care as I should									
☐ ¹ I may not take quite as much care									
☐ ⁰ I take just as much care as ever									
C4 I can laugh and see the funny side of things: <table border="1"> <tr><td>☐⁰ As much as I always could</td></tr> <tr><td>☐¹ Not quite so much now</td></tr> <tr><td>☐² Definitely not so much now</td></tr> <tr><td>☐³ Not at all</td></tr> </table>	☐ ⁰ As much as I always could	☐ ¹ Not quite so much now	☐ ² Definitely not so much now	☐ ³ Not at all	C11 I feel restless as if I have to be on the move: <table border="1"> <tr><td>☐³ Very much indeed</td></tr> <tr><td>☐² Quite a lot</td></tr> <tr><td>☐¹ Not very much</td></tr> <tr><td>☐⁰ Not at all</td></tr> </table>	☐ ³ Very much indeed	☐ ² Quite a lot	☐ ¹ Not very much	☐ ⁰ Not at all
☐ ⁰ As much as I always could									
☐ ¹ Not quite so much now									
☐ ² Definitely not so much now									
☐ ³ Not at all									
☐ ³ Very much indeed									
☐ ² Quite a lot									
☐ ¹ Not very much									
☐ ⁰ Not at all									
C5 Worrying thoughts go through my mind: <table border="1"> <tr><td>☐³ A great deal of the time</td></tr> <tr><td>☐² A lot of the time</td></tr> <tr><td>☐¹ Not too often</td></tr> <tr><td>☐⁰ Very little</td></tr> </table>	☐ ³ A great deal of the time	☐ ² A lot of the time	☐ ¹ Not too often	☐ ⁰ Very little	C12 I look forward with enjoyment to things: <table border="1"> <tr><td>☐⁰ As much as I ever did</td></tr> <tr><td>☐¹ Rather less than I used to</td></tr> <tr><td>☐² Definitely less than I used to</td></tr> <tr><td>☐³ Hardly at all</td></tr> </table>	☐ ⁰ As much as I ever did	☐ ¹ Rather less than I used to	☐ ² Definitely less than I used to	☐ ³ Hardly at all
☐ ³ A great deal of the time									
☐ ² A lot of the time									
☐ ¹ Not too often									
☐ ⁰ Very little									
☐ ⁰ As much as I ever did									
☐ ¹ Rather less than I used to									
☐ ² Definitely less than I used to									
☐ ³ Hardly at all									
C6 I feel cheerful: <table border="1"> <tr><td>☐³ Never</td></tr> <tr><td>☐² Not often</td></tr> <tr><td>☐¹ Sometimes</td></tr> <tr><td>☐⁰ Most of the time</td></tr> </table>	☐ ³ Never	☐ ² Not often	☐ ¹ Sometimes	☐ ⁰ Most of the time	C13 I get sudden feelings of panic: <table border="1"> <tr><td>☐³ Very often indeed</td></tr> <tr><td>☐² Quite often</td></tr> <tr><td>☐¹ Not very often</td></tr> <tr><td>☐⁰ Not at all</td></tr> </table>	☐ ³ Very often indeed	☐ ² Quite often	☐ ¹ Not very often	☐ ⁰ Not at all
☐ ³ Never									
☐ ² Not often									
☐ ¹ Sometimes									
☐ ⁰ Most of the time									
☐ ³ Very often indeed									
☐ ² Quite often									
☐ ¹ Not very often									
☐ ⁰ Not at all									
C7 I can sit at ease and feel relaxed: <table border="1"> <tr><td>☐⁰ Definitely</td></tr> <tr><td>☐¹ Usually</td></tr> <tr><td>☐² Not often</td></tr> <tr><td>☐³ Not at all</td></tr> </table>	☐ ⁰ Definitely	☐ ¹ Usually	☐ ² Not often	☐ ³ Not at all	C14 I can enjoy a good book or radio or TV programme: <table border="1"> <tr><td>☐⁰ Often</td></tr> <tr><td>☐¹ Sometimes</td></tr> <tr><td>☐² Not often</td></tr> <tr><td>☐³ Very seldom</td></tr> </table>	☐ ⁰ Often	☐ ¹ Sometimes	☐ ² Not often	☐ ³ Very seldom
☐ ⁰ Definitely									
☐ ¹ Usually									
☐ ² Not often									
☐ ³ Not at all									
☐ ⁰ Often									
☐ ¹ Sometimes									
☐ ² Not often									
☐ ³ Very seldom									

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

SECTION D: ABOUT YOUR NEEDS AS A CARER

These questions are about needs that some carers have identified. Please rate how important each item is from 0-10 as it relates to your present situation. If an item is not at all important to you, give it a 0. If it is very important to you give it a 10. If it is somewhere in between, give it a score between 0 and 10 which reflects how important it is for you. Then check whether each need is currently met or unmet.

	I need to:	If you rate an item higher than 0, please check if met or unmet		
		0-10	Met	Unmet
D1	Have my questions answered honestly			
D2	Know specific facts concerning the patients' prognosis			
D3	Feel that the professionals care about the patients			
D4	Be informed of changes in the patient's condition			
D5	Know exactly what is being done to the patient			
D6	Know what treatment the patient is receiving			
D7	Have explanations given in terms that are understandable			
D8	Be told about changes in treatment plans while they are being made			
D9	Feel there is hope			
D10	Be assured that the best possible care is being given to the patient			
D11	Know what symptoms the treatment or disease can cause			
D12	Know when to expect symptoms can occur			
D13	Know the probable outcome of the patient's illness			
D14	Know why things are being done for the patient			
D15	Know the names of health professionals involved in the patient's care			
D16	Have information about what to do for the patient at home			
D17	Feel accepted by the health professionals			
D18	Help with the patient's care			
D19	Have someone be concerned with my health			
D20	Be told about people who could help with problems			

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

SECTION E: ABOUT YOU			
This section contains questions about your background and domestic circumstances. This information will help us analyse and organise our results, and to be confident that our results are representative.			
E1	What is your gender?	☐ ¹ Male ☐ ² Female	
E2	What is your date of birth?		MM YYYY
E3	What is your current marital status? <i>Please tick one</i>	☐ ¹ Married or living as married ☐ ² Divorced or separated ☐ ³ Widowed ☐ ⁴ Single ☐ ⁰ Other <i>Please specify</i>	
E4	Do you have any other dependents for whom you personally provide care <u>locally</u> (children/grandchildren/elderly/ disabled)?	☐ ¹ No ☐ ² Yes <i>Please specify</i>	
E5	Which of these best describes your current employment status? <i>Please tick one</i>	☐ ¹ In paid work (including self-employment) – full or part time ☐ ² Temporarily off sick from my job ☐ ³ Unemployed ☐ ⁴ Retired from paid work ☐ ⁵ Unable to work because of long-term disability or ill health ☐ ⁶ In full-time education, training or work experience ☐ ⁰ Other <i>Please specify</i>	

Answering these questions is completely voluntary, so if you decide there are any questions you would rather not answer, please just go to the next question.

E6	Which of the following ethnic groups would you say you belong to? <i>Please tick one</i>	☐¹ White British ☐² White – Eastern Europe ☐³ White – other white groups ☐⁴ Black Caribbean ☐⁵ Black African ☐⁶ Black – other black groups ☐⁷ Asian – Middle East ☐⁸ Asian – Far East ☐⁹ Mixed background <i>Please specify</i> ☐⁰ Other <i>Please specify</i>
E7	What is your highest level of education?	☐¹ Secondary school ☐² University degree ☐³ University postgraduate: masters ☐⁴ University postgraduate: PhD ☐⁰ Other <i>Please specify</i>
E8	Do you have any additional comments about the topic of this questionnaire? <i>Please use the box provided (you can use the blank space at the end of this questionnaire if you need more space)</i>	

IMPORTANT: please read the information on page 13 about further work ➡

SECTION F: May we contact you again?

Thank you for your participation in this survey. The results will help us to better understand the experiences of people who are supporting a relative from a distance.

We are interested in learning more about your views and experiences as someone who is caring at a distance for a relative who is seriously ill. For the next part of our research, we would like to conduct telephone interviews, to ask you in more depth about this topic. You would only be required to have one single interview, which would last around 30-45 minutes. If you are interested to learn more and possibly take part in this research, please fill in your contact details below and we will be in touch.

Completing this expression of interest does not commit you to anything - Eligible participants will be given full details of the telephone interview study to allow them to decide whether or not they wish to take part.

Your contact details will be detached from the questionnaire and kept securely and **strictly confidential**. They will **not** be passed on to anyone else. We will keep a record to enable us to contact you about this study only. If you have any questions about this, please contact the Chief Investigator, Carolina Casañas i Comabella on 01865 482814 or 12090237@brookes.ac.uk.

Are you interested in learning more about the next phase of this study?
Please tick one

☐ **No, I am not interested**

Do not complete the section below.

☐ **Yes, I would like to learn more about this work**

Please complete contact details below.



Would you like to receive a summary of the study results by the end of the project?
Please tick one

☐ **No, do not send me a summary**

Do not complete the section below.

☐ **Yes, send me a summary at the end of the project**

Please complete contact details below.



Please give your contact details:

Name

Address

Home telephone

Work telephone

Mobile telephone

Email address

Postcode

Unique study ID

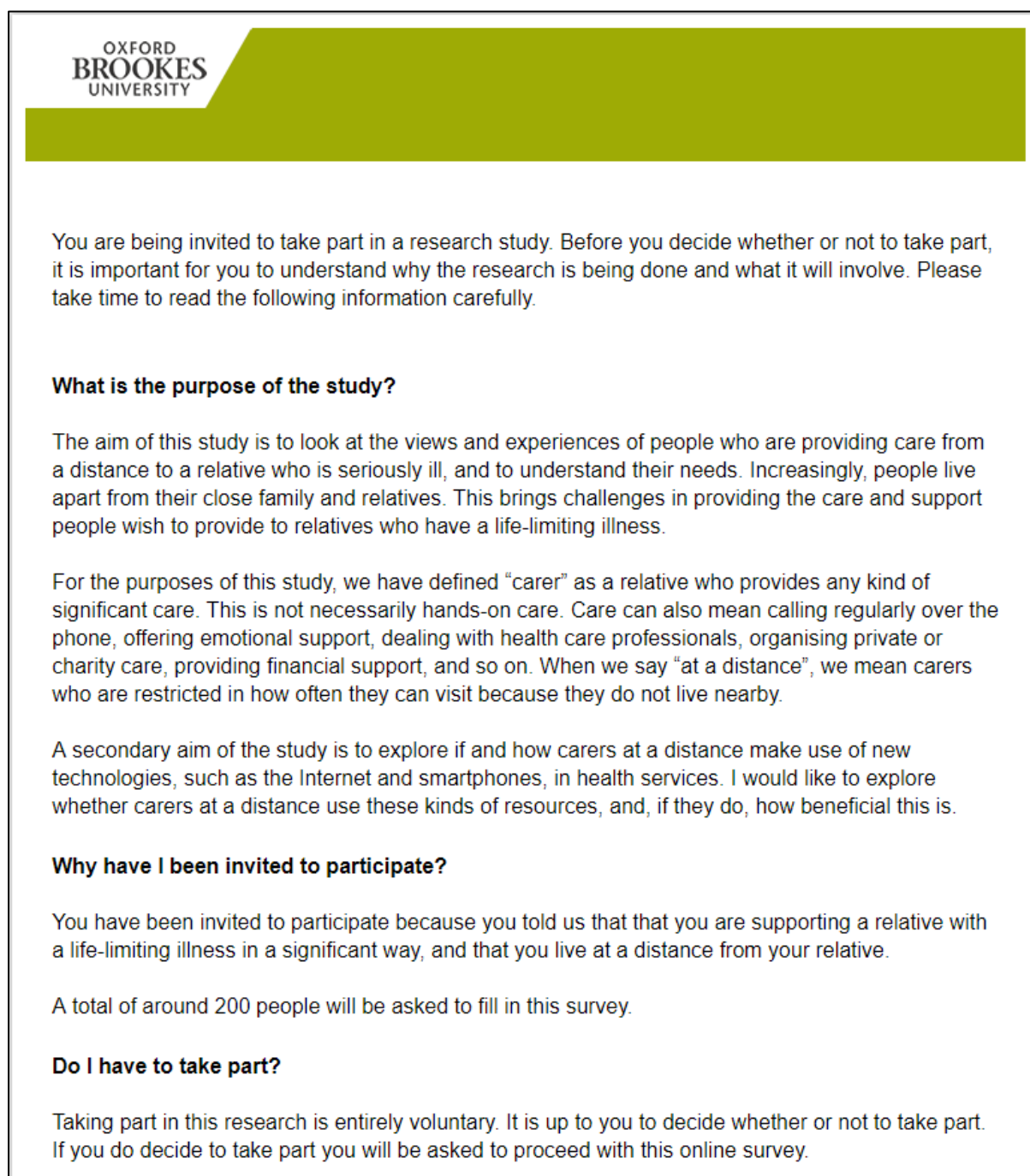
From the front of this booklet

Thank you for taking the time to complete this questionnaire. When you have finished, please return it in the reply paid envelope supplied to:

Carolina Casañas i Comabella
Faculty of Health and Life Sciences
Oxford Brookes University
Jack Straws Lane
Oxford
OX3 0FL

Appendix 4.7. Screenshots of the online version of the questionnaire

Below are a few screenshots of the online version of the questionnaire, which used the University's preferred style in terms of layout, colour scheme and font. Only a few pages are shown in this appendix.



**OXFORD
BROOKES
UNIVERSITY**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The aim of this study is to look at the views and experiences of people who are providing care from a distance to a relative who is seriously ill, and to understand their needs. Increasingly, people live apart from their close family and relatives. This brings challenges in providing the care and support people wish to provide to relatives who have a life-limiting illness.

For the purposes of this study, we have defined "carer" as a relative who provides any kind of significant care. This is not necessarily hands-on care. Care can also mean calling regularly over the phone, offering emotional support, dealing with health care professionals, organising private or charity care, providing financial support, and so on. When we say "at a distance", we mean carers who are restricted in how often they can visit because they do not live nearby.

A secondary aim of the study is to explore if and how carers at a distance make use of new technologies, such as the Internet and smartphones, in health services. I would like to explore whether carers at a distance use these kinds of resources, and, if they do, how beneficial this is.

Why have I been invited to participate?

You have been invited to participate because you told us that that you are supporting a relative with a life-limiting illness in a significant way, and that you live at a distance from your relative.

A total of around 200 people will be asked to fill in this survey.

Do I have to take part?

Taking part in this research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to proceed with this online survey.

We would like to ask about your experience, which will help us to better understand the experience of providing support to a loved one from a distance.

Participation in this research study is voluntary. If you do decide to participate in the postal survey, please complete the questionnaire. By doing this, you consent for us to use your responses in our research. It will take you about 20 minutes to complete the questionnaire.

When the survey has been completed, I will be conducting some telephone interviews. If you are interested in finding out more about this and possibly taking part, please fill in your contact details in section F. Even if you send back your details, you are under no obligation to take part. If you are not interested, please leave that section blank when you return your questionnaire.

Please read each question carefully. There are no right or wrong answers to these questions. If you decide there are any questions you would rather not answer, please just go to the next question.

All the information you give will be treated as strictly confidential

If you have any questions about any aspect of completing the questionnaire please contact the Chief Investigator of this study:

Carolina Casañas i Comabella
Telephone: 01865 482814
Email: 12090237@brookes.ac.uk

Thank you very much for your help

BACK

NEXT



What is the relationship of the local carer(s) to you?

Please tick all that apply

- ☐ The person who provides care locally is my relative *Please specify*
- ☐ The person who provides care locally is a friend of my relative
- ☐ The person who provides care locally is someone I employ
- ☐ I do not have a relationship with the person who provides care locally
- ☐ Other *Please specify*

How far do you live from your relative?

- ☐ Ten miles or less
- ☐ Between 11 and 30 miles
- ☐ Between 31 and 50 miles
- ☐ Between 51 and 100 miles
- ☐ More than 100 miles within the UK
- ☐ I live in a different country – *less than 1 day travel*
- ☐ I live in a different country – *more than 1 day travel*

How long does it take you to get to your relative?

- ☐ Less than 1 hour
- ☐ One to 3 hours
- ☐ Half a day
- ☐ More than half a day

When you have used the internet in your role as a carer, what have you used it for?

Please tick all that apply

- ☐ To find out information about the health problem of my relative
- ☐ To find out about practical aspects for my relative (for instance, how can he or she contact a hospital or how can he or she get there)
- ☐ To book an appointment with doctor/nurse for my relative
- ☐ To find out information about how to provide support
- ☐ To share my experiences as a carer with other people (for instance, an online forum for carers)
- ☐ Other *Please specify*

Overall, how helpful have you found using the internet *in your role as a carer*, in relation to *your relative's needs*?

- ☐ Very helpful
- ☐ Somewhat helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ I don't know

Appendix 4.8. The interview topic guide

The topic guide for the semi-structured interview included:

a) Questions about caring exploring:

- The kind of care and support that the carer at a distance provides.
- When did this situation start; how did the distance come about.
- Examples of when caring at a distance has been difficult/easier.
- Their needs as carers at a distance.
- Whether and how they get in touch with the people who are looking after their relative locally (other relatives, clinical team).

b) Questions about ehealth exploring:

- Whether and how they have used ICT to support.
- Their role as a carer in any way (e.g. information, online support groups for carers).
- Whether and how they have used ICT to support to keep in touch with their relative.
- Reasons why they have not used ICT when caring at a distance.
- Potential risks and/or benefits of using ICT as carers at a distance.

Appendix 4.9. Consent form



CONSENT FORM

Title of Project: **Carers at a distance in palliative care: a mixed-methods study exploring the role of e-health.**

Name of Researcher: **Casañas i Comabella, Carolina**

Please initial box

1. I confirm that I have read and understand the information sheet (version 2.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
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. ☐
3. I understand that any data generated in the course of the research will be retained in accordance with the University's policy of Academic Integrity and will be kept securely in paper or electronic form for a period of ten years after the completion of the research. ☐
4. I agree to take part in the above study. ☐
5. I agree to the interview being recorded and transcribed. ☐
6. I agree that quotations from my interview can be used anonymously in the presentation of the overall research findings, including journal publications and feedback to relevant health professionals. ☐

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Appendix 4.10. Participant Information Sheet

[Brookes headed paper]

Study title:

Carers at a distance in palliative care: a mixed-methods study exploring the role of ehealth.

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The aim of this study is to look at the views and experiences of people who are providing care from a distance to a relative who is seriously ill, and to understand their needs. Increasingly, people live apart from their close family and relatives. This brings challenges in providing the care and support people wish to provide to relatives who have a life-limiting illness.

For the purposes of this study, we have defined “carer” as a relative who provides *any kind* of significant care. This is not necessarily hands-on care. Care can also mean calling regularly over the phone, offering emotional support, dealing with healthcare professionals, organising private or charity care, providing financial support, and so on. When we say “at a distance”, we mean carers who are restricted in how often they can visit because they do not live nearby.

A secondary aim of the study is to explore if and how carers at a distance make use of new technologies, such as the Internet and smartphones, in health services. I would like to explore whether carers at a distance use these kinds of resources, and, if they do, how beneficial this is.

Why have I been invited to participate?

You have been invited to participate because your relative indicated that you are supporting him or her in a significant way, and that you live at a distance.

A total of around 200 people will be sent a postal survey.

Do I have to take part?

Taking part in this research is entirely voluntary. 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 without giving a reason, until such time as the data are analysed. Choosing to either take part or not take part in the study will have no impact on the care that your relative is receiving.

What will happen to me if I take part?

For the first part of my study, I would like to conduct a postal survey with carers at a distance. I will be looking at people who are providing informal, unpaid care at a distance for a relative with a life-limiting illness. After the postal survey, I plan to conduct telephone interviews with about 20 to 30 carers to explore these topics in more depth. If more than 30 people express interest in taking part in the interview, I may not be able to interview all of them.

If you decide to take part, you will be asked to complete the questionnaire enclosed with this letter and send it back to me in the FREEPOST self-addressed envelope also enclosed. Completing the questionnaire should take you around 15 minutes.

At the end of the questionnaire you will be asked if you would be willing to also take part in a telephone interview (or face to face or video-conference if you prefer so). This interview will last around 30 minutes and you will be asked about the same topics in the questionnaire, but in more depth this time.

Your participation in the study will depend on how much you wish to be involved. You can choose to only reply to the questionnaire.

What are the possible benefits or risks of taking part?

There are no direct benefits or risks of taking part in this study. However, you may feel that it is beneficial for you to talk about your role as a family member providing care. The information gained through this study will help us understand the views and experiences of carers at a distance. We hope that this will inform healthcare professionals who provide care to those in similar circumstances to you and your relative. Ultimately, we hope to improve the experiences of others living with life-limiting illnesses and their families.

Equally, there is a chance that you might find talking about these issues upsetting. If this is the case, you may want to contact Carers UK on 0808 808 7777 or visit the Carers UK website

on <http://www.carersuk.org>. In the event that you found the telephone interview distressing, we could stop at any time.

Will what I say in this study be kept confidential?

Yes. Confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material.

The results of the study will be written up for a PhD thesis and will also be published in academic journals. Any publication of the findings will be completely anonymous (you will not be identified in any way). No names will be used: if you decide to participate, you will be assigned a numeric code, which will be used in any research material or publications. The findings will also be presented to clinical departments participating in the study and at relevant conferences.

Please note that if the responses to the questionnaire suggest that you might be experiencing significant anxiety or depression issues, I will suggest that you contact your GP about it, who may be able to help you. This is standard research practice. I will not contact the GP myself.

In accordance with Oxford Brookes University's policy on academic integrity, the data produced in the course of this research will be retained for a period of 10 years after the completion of a research project, securely held in a locked cupboard.

What should I do if I want to take part?

If you want to take part in this study, please complete the questionnaires enclosed in this letter and post them back to me in the FREEPOST self-addressed envelope enclosed.

If you wish to be interviewed after the questionnaire, please fill in page 15 of the questionnaire, as well as the consent form, before you send it back to me. If you only wish to complete the questionnaire, but do not want to be interviewed, please leave page 15 of the questionnaire blank. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care that you or your relative receive.

What will happen to the results of the research study?

The results of the research will be used in my PhD thesis. I will also aim to disseminate the results by presenting at relevant national and international conferences, and by publishing in scientific journals.

A copy of the final PhD thesis will be accessible through Oxford Brookes University. At the end of the study, I would like to send you a letter thanking you for your participation in the study. If you would

like a summary of the results at the end of the study, please tick the box provided at the end of the questionnaire.

Who is organising and funding the research?

I am conducting this research as a PhD student in the Department of Clinical Health Care, at Oxford Brookes University, under the supervision of Prof Mary Boulton, Prof Eila Watson and Prof Bee Wee.

This PhD is funded by the NHS South East Health Strategic Authority.

Who has reviewed the study?

This research project has been approved by the Faculty Research Ethics Committee, Oxford Brookes University, and by the NHS Research Ethics Committee REC South-Central, Oxford C.

Contact for Further Information

You may contact me or my Director of Studies Prof Boulton, should you have any questions.

Professor Mary Boulton +44 (0)1865 485298
mgboulton@brookes.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on heabbott@brookes.ac.uk.

Thank you very much for taking time to read this document.

Oxford, 11th February 2014