**END OF LIFE CARE IN THE HOME:
SUPPORTING AND SUSTAINING FAMILY CARERS**

By

Jacqueline Rose Bowden-Tucker

A thesis submitted to the Victoria University of Wellington
in partial fulfilment of the
requirements for the degree of
Masters of Arts (Applied)
in Nursing

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Abstract

Palliative care services within New Zealand aim to support care for terminally ill people and their family/ whānau, regardless of their disease or place of care. Increasingly consumers prefer that this care and support, including end of life care, is provided in their own home as opposed to hospital or care institutions and current health policies support this trend. The availability of family carers is widely acknowledged as pivotal to home palliation by ensuring physical care and emotional support for the patient is available outside that provided by formal (paid) carers and palliative care professionals entering the home.

Literature searched found that family carers feel under prepared for their role and desire more support and information from health care professionals. How to achieve this is less clear. When considered against the backdrop of an ageing population and geographically dispersed families, it is forecast there will be increased incidence of dying patients with complex palliative care needs and a reduced carer population that may make the preference for home death increasingly problematic.

Using purposive sampling techniques, six bereaved family carers, who were enrolled with a hospice palliative care service (HPCS) and had supported end of life care of a relative at home, were recruited. Utilising qualitative descriptive methodology this study sought to identify the key conditions under which their caring contribution was sustained. Data collection was by way of semi-structured interviews that were audiotaped and transcribed. Following coding, transcripts underwent qualitative content analysis and revealed three key themes and associated subthemes relating to: perception and acquisition of caring role; sustaining the role; now and looking back. Conclusions drawn from this research offer increased understanding of the enabling factors family carers experienced as supporting them in their role and achieving a home death for their relative.

Key words

Family carers, palliative care, dying at home, end of life, community

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Chapter 1. Introduction

Globally, as populations are ageing, life expectancies increasing and illness trajectories lengthening, the demand for palliative care services continues to escalate (Gomes & Higginson, 2008; Perreault, Fothergill-Bourbonnais, & Fiset, 2004). Combined with economic recession, respected commentators within palliative care suggest these disease related and demographic trends will unavoidably result in the need and demand for palliative and end-of-life care to exceed professional and financial resources (Monroe, 2010; Monroe, Hansford, Payne, & Sykes, 2007).

Most recently, within New Zealand, projected populations by age group have been quantified to determine future palliative care need (Palliative Care Council, 2011). It is estimated that within the next 15 years, the number of people aged 65 and over will have risen from 12.2% in 2006 to 18.9% in 2026, and for the same period people aged over 85 years old will rise from 1.4% to 2.3%. Mortality trends and forecasts in the wake of these demographic estimates herald an anticipation of increased demand for palliative and end of life care.

Palliative care services within New Zealand aim to support care for terminally ill people and their families, regardless of their disease or place of care (Ministry of Health, 2001). This intent, if to be fully realised, must be considered against the backdrop of key drivers that underpin this ethos and potential challenges that could diminish it. Increasingly consumers prefer that this care and support, including end of life care, is provided in their own home as opposed to hospital or care institutions and current health policies support this trend (Hudson, Aranda, & McMurray, 2002; Visser et al., 2004). The availability of family carers is widely acknowledged as pivotal to home palliation by ensuring physical care and emotional support for the patient is available outside that provided by formal (paid) carers and health professionals entering the home (Visser et al., 2004).

With these challenges in mind there is growing awareness that new approaches to providing palliative and end of life care are required. New models of care that enable the role of family and communities in care of the dying, support resilience and disseminate palliative care knowledge are widely advocated (Addicott & Ashton, 2010; Gomes & Higginson, 2006; Grande et al., 2009; Leadbeater & Garber, 2010; O'Connor, Davis, & Abernethy, 2010).

1.1 Background to the study

The aim of this research, to explore and describe the key conditions under which family carers who supported the death of a relative at home were able to sustain their contribution of care, evolved primarily from my participation in an independently facilitated strategic planning day. Held by a Hospice Palliative Care Service (HPCS) located within a high retirement region in New Zealand, this day was intended to appraise current service provision and identify priorities for future development of the service. The service comprises a specialist interdisciplinary palliative care team, a purpose built six-bed inpatient hospice unit, a community palliative care nursing team, a 24 hour telephone support and on-call nursing service for community patients, provision of a regional palliative care education programme and a family (bereavement) support service (FSS).

Attendees at the day represented a cross-section of the clinical and management team. Amongst discussions held consensus was particularly strong that current supports and interventions addressing the needs of family carers supporting someone with terminal illness in the community were underdeveloped. Anecdotal observations of attendees were that this may have had a negative impact on the coping of some family carers and their ability to support planned end of life care at home. In the preceding year, service statistics indicated 143 patients receiving palliative care via the service had died, with place of death recorded as: hospice inpatient unit = 53 (37%); home = 34 (24%); private care facility = 40 (28%); hospital = 16 (11%). With the number of home deaths trailing all other settings except hospital, the proposal to investigate the establishment of a day programme /respite facility and carer support programme to address perceived unmet carer needs began to evolve. To ensure any service developments were viable, responsive to family carers needs and provided in a manner acceptable to them (Grande et al., 2009), research of the perspectives of the intended user group became my focus.

As the palliative nurse educator (PNE) for the service, clinical education and continuing development of palliative care nursing practice both within the service and externally within generalist palliative care settings is my primary role. My own clinical practice within the service includes periodic duties within the inpatient unit or community team, the latter being the clinical setting to which I ascribed greatest passion. Working with people in their own homes is a privileged endeavour, which offers considerable access to establishing an

understanding of the individual patient, their family, beliefs, culture, aspirations, fears, loves and losses. When supporting individuals living with, and dying of, terminal illness and those important to them, developing an understanding of their unique response and perspectives is foundational to my nursing practice.

1.2 Overview of study

This thesis has been separated into five chapters. Following the first introductory chapter, Chapter 2 offers an overview of literature reviewed to ascertain current knowledge of informal caring at end of life care in the home environment. Summary and critique of the literature is presented alongside explanation of how it influenced the design of the present study. Chapter 3 provides an outline of the research design and methodology including recruitment, data collection and data analysis processes. The study's findings are presented in Chapter 4 with the key themes derived from the data outlined. Discussion of the findings as they relate to current literature is presented in Chapter 5 alongside study limitations, and my reflections on becoming a researcher. Finally conclusions and recommendations are offered on how the findings may influence practice and service development in the future.

1.2 Explanations, definitions and key terms

Formal carers – paid carers employed by community support care services to, upon referral, provide in-home physical care and/or household management for patients and their families. Whilst some degree of training has been undertaken by formal carers they are an unregulated workforce. Within the literature this role attracts varying titles including health care assistants, home care workers. To avoid confusion this study report will use the title 'formal carers' in reference to this group.

Family carer – the main person who provided unpaid practical and emotional support to the patient on a regular basis and was in contact with the palliative care team (Walsh et al., 2007, p. 142). Within the literature other variations on the role title include informal carers, lay carers and primary carers. To avoid confusion, this study report will use the title 'family carers' in reference to this group. In using this term it is acknowledged that varied social and cultural constructs of 'family', in some instances, extends beyond shared biological, social, or legal ties (Payne, 2004).

Home – Private residence in which care and eventual death of the patient occurred.

Palliative care – Is an approach that improves the quality of life of patients and their families facing the problems 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 (World Health Organisation, 2002).

End of life care – pertains to the support of people living with progressive, end stage illness or disease up to and including the final days and hours of life.

Palliation – to palliate a disease is to treat it partially and insofar as possible, but not to cure it completely. Palliation cloaks a disease. Retrieved on 03/07/10 from www.medterms.com/script/main/art.asp?articlekey=9048

Chapter 2. Literature review

2.1 Introduction

The literature review that has supported this study was conducted in two distinct phases. To develop this research topic from initial ideas into a comprehensive study proposal and design, an initial literature review was undertaken to ascertain current knowledge of informal care at end of life in the home environment. Whilst not exhaustive this initial search, exploration and synthesis of identified literature influenced the formation and positioning of the research proposal and current study. A secondary literature review occurred throughout the study and following data analysis to extend the initial review and accommodate reflexivity as my thoughts in relation to findings evolved. This chapter offers a description of how the initial literature review was conducted, a précis of the key themes identified and how they linked to provide the platform for the present enquiry. Articles in the second phase of the literature review were mostly obtained via colleagues, my supervisor and brief database searches in response to evolving study findings. Critique of this literature has been embedded in the discussion chapter 5.

2.2 Conducting the initial literature review

Databases explored included Pubmed, PsycINFO, the Cumulative Index to Nursing and Allied Health (CINAHL), Te Puna and Proquest. Databases were searched for studies published between 2001 – 2010 using various combinations of the following keywords, “terminal care”; “palliative care”; “end of life”; “caregiver perspective”; “informal carers”; caregiver; “home palliation”; “hospice in the home”; and “community”. Searches were continued until saturation was reached in terms of multiple hits between databases of the same studies and/or no new themes were being identified within study findings. Further items and resources were identified by way of manual library searches and through key contacts within Hospice New Zealand. Wider discussions with colleagues in both specialist and generalist palliative care also lead to identification of some items.

Items were then filtered to exclude any in which the care giving context was either not specified or the recipient of care was not indicated to be terminally ill (as in the case of persons with intellectual or physical disability), as these studies were considered outside the focus of the present study. The rationale for this exclusion is made more apparent later in this chapter as the unique nature of informal care at end of life is described within the literature presented. Studies reporting carer perspectives where the care recipient did not achieve their preference to die at home, perhaps requiring an unplanned inpatient admission for terminal care, were not automatically excluded. It was recognised these studies offered significant insight into informal care in the home preceding the transfer and factors perceived by carers that contributed to decision-making for admission.

2.3 Existing knowledge

Informal care at end of life has received substantive research focus over the last decade, evolving a significant body of knowledge. Multiple social and health care trends appear to have provided significant impetus for this research. There is recognition by constituents that the increasing reliance on family carers in this care context must be reciprocated with increased understanding and support of the role and more importantly those who assume it (Grande et al., 2009). Research obtained has been grouped into three key areas of knowledge for discussion: Informal care at end of life; carer burden and coping; caring for the carers.

2.4 Family care at end of life

The experience of caregiving for a loved family member or friend, who is dying at home, can prove both deeply meaningful and potentially traumatic (Rabow, Hauser, & Adams, 2004). There are complex adjustments to negotiate in terms of changing relationships and roles between the carergiver, the care recipient and other formal and family carers during this time (McMurray, 2004). Significant onus rests on health professionals to understand these unique aspects and where possible, enable both the experience and associated memories to be as positive as possible for those who remain (Eyre, 2010).

2.5 Drivers for end of life care in the home

Internationally, the rapid rise of the modern hospice movement has supported a global trend towards provision of palliative care within the community and home environment and garnered consumer expectation for end of life care at home to be an accessible option to those

who desire it (Hudson et al., 2002). Similarly, fiscal constraint of health care budgets have reinforced health and social policy trends toward community and home based care where family carers are increasingly assuming and providing significant contributions of care alongside formal (paid) and professional carers (Aoun, Kristjanson, Currow, & Hudson, 2005; Visser et al., 2004).

Also to be acknowledged is the reality that some people may not wish to die at home and for those who do, their preferences may be superseded in time by circumstances that precipitate institutional admission such as: carer burden, uncontrolled symptoms or a potential decision shift towards end of life (Monroe et al., 2007; Visser et al., 2004). Some research findings have also highlighted the attitudes of some older people towards 'home' as a place of care at end of life, to mean more than a physical location but rather denoted in symbolic terms as being surrounded by 'familiarity, comfort the presence of loved ones' (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004 p.460).

In relation to an individual's preference to die at home, the evidence is strong that the contribution of family carers is central to achieving optimum home palliation. Without their contribution of physical care and emotional support for the patient above and beyond that of formal (paid) carers and palliative care professionals entering the home, a patient choice to die at home is improbable (Grande et al., 2009). How best to support and sustain the care contribution of family carers within this context is gaining urgency.

2.5.1 Role and needs of family carers

Home palliation and the role and needs of family carers within this context, has attracted significant research attention. Grande et al. (2009) presents a comprehensive review and analysis of much of this work, which reflects a role that is diverse and complex in nature, with inherent responsibilities and tensions for those who assume it. Caring activities are recognised to fluctuate in number and intensity throughout the care recipient's illness and may include aspects of physical care, medicine management, emotional support, symptom monitoring, advocacy and seeking help, financial management, transport and mobility assistance (Clark et al., 2007; Zapart, Kenny, Hall, Servis, & Wiley, 2007).

Clark et al. (2007) explored the perspectives of family carers supporting people with chronic heart failure at home, illuminating the complexities and nature of informal care in protracted illness trajectories. Findings suggested endeavours of carers to foster independence and

effective symptom management for the patient, were principally based upon higher goals to maintain patient independence and normality within the bounds of an essentially 'disruptive and unpredictable' (ibid, p. 380) disease. Recognising subtle changes and responding to the patients capacities were based upon their intimate knowledge of the individual and learned understanding 'of hourly and daily fluctuations' (p. 378).

The vital role and responsibility often entrusted to carers in the home to monitor and manage symptoms was captured in a qualitative case study, highlighting the considerable degree to which health professionals relied on carer assessments of the patient's condition to provide cues for action (Armes & Addington-Hall, 2003). It is perhaps unsurprising to note therefore, that a significant and consistent request from carers within the literature is for more information and support from health professionals that is personalised to their needs along the patient's illness trajectory (Perreault et al., 2004).

2.5.2 Changing carer demographics

Family carers are an increasingly heterogeneous group. Changing carer demographics in terms of age and marital status, were captured in results of a large population-based survey (n= 18,267) conducted in South Australia, between 2000 and 2005, on caregivers of patients with end stage lung disease (ESLD) (Currow, Ward, Clark, Burns, & Abernethy, 2008). Respondents included carers (n=104) of varying relationship to the patient who provided day-to-day or intermittent hands-on care for someone who died from ESLD including spouse (15.9%), parent/child (36.9%), sibling (7.2%), other relative (30.4%), or friend (9.7%). This work asserts that spousal caregivers, who have largely occupied the focus of carer research to date, may not be the predominant carer group in future generations.

Recent research has begun to extend the research focus from primarily spousal caregivers, to explore the wider construct of informal end of life care for older persons in the community and what characteristics of that care were associated with dying at home (Visser et al., 2004). Results reinforced the significant contribution of family carers in this context illuminating the wider carer networks that can evolve, comprising of primary family carers supported by

secondary family carers. Importantly this study demonstrated a strong association between home deaths and the burden felt by carers, suggesting ‘institutional admissions before death are strongly associated with caregiver burden’ (ibid, p. 474). They further conclude the availability of secondary informal carers increases the feasibility of end of life care in the home.

Identifying the primary family carers of patients can be problematic. Patients may have a network of carers owing to changing family structures (blended families) and geographical dispersal, further preventing assumptions that spousal carers or next-of-kin are the main support (Grande et al., 2009). Payne (2004) makes a further distinction of what constitutes family, acknowledging that varied social and cultural constructs of ‘family’, in some instances, extends beyond shared biological, social, or legal ties. She also acknowledges for some individuals their families do not offer repose or nurture their wellbeing, as in abusive or exploitative relationships. Regardless of such distinctions what is essential to acknowledge is that families are ‘dynamic social structures’ within which there are ‘complex social systems of reciprocal demands and support’ (p. 183). The impact these combined trends may have in the future on the availability of family carers who are able and/or willing to support home palliation and end of life care is unclear and warrants further research that falls outside the present enquiry.

2.6 Caregiver burden and coping

As previously stated it is well recognised that optimal care of the dying in the home environment is reliant on the availability and capability of family carers. Potential for carer burden is well documented within the literature where added emotional, financial, and physical stress inherent in the role has been found to precipitate reduced coping and compromised health of carers, premature mortality, depression and restriction of activities (Abernethy, Burns, Wheeler, & Currow, 2009). The long term chronic illness trajectories of some people also raises concerns of the physical and emotional wellbeing of family carers and the continual demands made on them (Currow et al., 2008). It is suggested improving supports to sustain carers in this context requires recognition and understanding of the unique challenges, stresses and outcomes of end-stage caregiving (Waldrop, Kramer, Sketchy, Milch, & Finn, 2005). However, it is also argued that the predominant stress model approach to

researching family caregiving may not recognise or acknowledge the natural resilience and strength some carers may bring to the situation (Bainbridge, Krueger, Lohfeld, & Brazil, 2009; Waldrop et al., 2005).

2.6.1 Unmet carer needs

Consistently reported by family carers within the literature is that they frequently feel underprepared for their role and desire more information and support from health professionals (Aoun et al., 2005). Lack of support from health professionals and diminished social networks as illness progresses can precipitate carer feelings of isolation, fear and helplessness associated with inability to relieve pain and discomfort, accelerating decisions for inpatient admissions (Milberg & Strang, 2004; Perreault et al., 2004). Further there is criticism that current service provision for carers is predominantly reactive and only instigated in crisis situations when there is apparent breakdown in the home situation (Aoun et al., 2005).

A study exploring the experiences of male caregivers involved in end of life care, focused on caregiver strain and reported that on enquiry men are less likely to acknowledge caregiver strain and if they do, responses are typically brief and understated (Fromme et al., 2005). It is difficult to draw strong conclusions from this work as there is a paucity of research on male caregivers in this context, however findings advocate that health professionals be proactive in their enquiries as males are less likely to volunteer their struggles unless asked. Whilst gender differences amongst family carers are not explored in depth here, it propelled my quest to ensure a male perspective is obtained in the present study's sample.

2.6.2 Barriers to optimal carer support

Hudson, Aranda and Kristjanson (2004), usefully and comprehensively describe potential barriers to supportive family care as existing at multiple levels including that of the family, the health system and communication process barriers. They suggest that within some families' incongruent communication, relationships and information needs can be complex for health professionals to negotiate and assess.

Similarly the predominant altruism of family carers can impede assessment, where carers appear hesitant or ambivalent to acknowledge or view their own needs as relevant or deserving above those of the patient (Morris & Thomas, 2002; Soothill et al., 2001). Key to countering this altruism is consistent acknowledgement and reassurance by health

professionals and services that caregiver needs are legitimate and their care contribution is essential, considerable and valued (Thomas, Morris, & Harman, 2002).

Communication process barriers can relate to compromised ability of family carers to “absorb and retain information” due to sleep deprivation and emotional stresses and/or limited disclosure by or between patients and carers, impairing identification of needs by health professionals (Hudson et al., 2004, p. 21). Further the health system itself can impose barriers in terms of finite health budgets limiting available services, lack of service continuity and co-ordination, and in some instances limited palliative care knowledge, skill and capability amongst some health professionals (ibid).

Ambiguity as to how the family carer role is conceptualised as both a provider of care (carer) and care recipient (co-client), is thought to contribute to potential unmet needs and at times marginalisation of carers within both social welfare and health care systems (Aoun et al., 2005; Harding, Leam, Pearce, Taylor, & Higginson, 2002; Morris & Thomas, 2002). For example tensions may occur due to the practitioner’s duty to maintain patient confidentiality resulting in potential failure to recognise the carers need for information as crucial in attaining competency as a carer, or differing from informational needs of the patient (Morris & Thomas, 2002). In practice, it is suggested family carers continue to be predominantly viewed and assessed by health care professionals as an appendage to the patient, contributing to a lack of recognition and acknowledgement of their own individual views, needs and desires (Payne, 2004). Similarly there has been critique that the ethos palliative care espouses, to view patients and families as a unit of care, may not be the experience of all consumers, with some studies reporting instances where health professionals have lacked sensitivity for the role of family in palliative care contexts (Oliviere & Monroe, 2004; Proot et al., 2003).

As the discussion here illustrates, potential barriers to optimal carer support can be multiple and complex and result in unmet needs. Equally for such impediments to be identified and addressed, a global perspective is required that is context sensitive to the individual carer, family, community and health environment:

It is more than a matter of providing greater resources for end of life care; policy makers, health service providers and health professionals should be alerted to the many roles played by informal carers and be responsive to their particular needs. (McNamara & Rosenwax, 2010, p. 1041)

2.7 Caring for the carers

2.7.1 Carer interventions and their effectiveness

The impact of care giving and the unmet needs of family carers have been well explored and reported within the literature. It is suggested the challenge for health and social services, is to find ways to minimise the negative aspects of caring and support the physical and emotional wellbeing of family carers who are in turn supporting the needs of those with an increasing symptom burden often associated with end stage disease (Currow et al., 2008). However, current knowledge of caregiver interventions and their effectiveness within this context are largely underdeveloped (Harding et al., 2002).

2.7.2 Positive aspects of caring

Whilst not ignored, the positive aspects of caring are less explored and in particular, developing greater understanding of proactive ways to minimise carer burden and increase emphasis on supporting carer strengths, resources and skill building is advocated (Grande et al., 2009). Wong, Ussher and Perz (2009) explored the positive aspects of caring as subjectively constructed by bereaved family carers and identified three key themes: discovering personal strength; relationships developed or enriched with the care recipient; and personal growth. This work acknowledged that the act of performing caring activities and the associated demands and challenges were, for some participants, constructed as an expression of love for the person for whom they cared not difficulties to be overcome. Building an appreciation of the inherent resilience of human nature that can accompany difficulties in life and death is a feature of such work. A useful definition of resilience within this context has been offered by Waldrop et al. (2005) “Resilience is the ability to withstand and rebound from disruptive life challenges through a process of adapting to adversity, such as providing end-stage care” (p. 636).

Whilst there is acknowledgement from some quarters that many caregivers appreciate the opportunity to care, are resilient, and will not suffer clinically significant distress or complex grief as a result of their experience, there remains a paucity of knowledge from this perspective (Murray et al., 2010).

2.8 Implications for the study

Through review of the literature it is evident that informal care at end of life has attracted significant research focus, generating a considerable body of knowledge. There is consensus that family carers are providing essential and increasingly complex physical care and emotional support for terminally ill people above and beyond that of formal (paid) carers and palliative care professionals entering the home (Aoun et al., 2005). The challenge posed for health and social services, is to find ways to minimise the negative aspects of caring and support the physical and emotional wellbeing of family carers who are in turn supporting the needs of those with an increasing symptom burden often associated with end stage disease (Currow et al., 2008).

Whilst this literature review is not exhaustive, it allowed me to identify some key areas for further enquiry. In particular extending existing knowledge of informal end of life care in the home from the position of those who have assumed the role and illuminate the prevailing supports and conditions they deemed to have enabled them to sustain their contribution of care. The following chapter outlines my approach to the study, in terms of aims and methodology including, recruitment, data collection and analysis, ethical considerations and strategies utilised to enhance credibility and transferability of the findings.

Chapter 3. Methodology

3.1 Introduction

The following chapter presents an overview of the research design and methodology used in this study including: setting, participants, recruitment, data collection and analysis, Treaty of Waitangi considerations and obligations, ethical considerations and finally, strategies utilised to enhance credibility and transferability of study findings. Following review of the literature, the research question was distilled and refined. The intention of this enquiry was to extend existing knowledge of informal end of life care in the home from the perspective of family carers and in particular increase understanding of the enabling factors carers experienced as supporting them in their role.

3.1.1 Aims & objectives

The research aim was to understand the key conditions under which family carers, who supported end of life care in the home, were able to sustain their contribution of care. The objectives of this study were to explore and describe:

- The informal care contribution of participants in this role.
- The informational, practical and emotional supports engaged and experienced by family carers.
- Formal and informal support networks engaged and experienced by family carers.
- Self identified strengths and skills family carers consider to have enabled and sustained their contribution of care.

3.2 Research design and methodology

Research consists broadly of two key approaches, namely quantitative and qualitative each of which purports varied schools of thought as to the nature of a phenomena, the way it can be studied and by which research designs and methods (Parahoo, 2006). Quantitative research is underpinned by the assumption that human phenomena are acquiescent to objective study and measurement, within quantifiable variables, producing results that can be replicated and generalisable (Parahoo, 2006). Strongly based within traditional scientific method, a quantitative researcher systematically moves from stating in advance a research question or

hypothesis, to observing it through a set of disciplined procedures that impose control over research conditions, to minimise biases and maximise precision and validity of results, subsequently reported in statistical or numerical language (Parahoo, 2006; Polit & Beck, 2006).

The qualitative research paradigm, by contrast, is utilised across a variety of social science disciplines and assumes reality is not a fixed entity but a subjective, context bound construct (Polit & Beck, 2006). The overarching goal within qualitative enquiry is therefore to interpret or reconstruct subjective meanings of the lived experience of study participants (Bailey, 1997). Realities therefore can be multiple and the qualitative researcher is not invested in manipulating or pre-empting the phenomenon being explored, as in the case of quantitative research, but remains open to it unfolding naturally (Patton, 2002). Essentially embedded within constructivist epistemology, qualitative research rejects the notion there is objective truth waiting to be discovered advocating instead truth and meaning “comes into existence in and out of our engagement with the realities of the world. There is no meaning without the mind. Meaning is not discovered it is constructed” (Crotty, 1998, p. 8-9). Qualitative research and methods are predominantly ‘inductive, interactive, holistic’ and ‘carried out by flexible and reflexive methods of data collection and analysis’ (Parahoo, 2006, p. 63).

It is important to acknowledge that discussing both quantitative and qualitative research approaches is not to suggest that they are polar opposites or that one approach is exclusively more useful than another. Indeed some research questions may benefit from a combination of both qualitative and quantitative research methods (Crotty, 1998). Patton (2002), offers a pragmatic approach to decisions concerning which research design or method to employ stating that “some questions lend themselves to numerical answers; some don’t” (p.13). In relation to the present study I deemed quantitative research methods to be too reductionist in approach and lacking the flexibility required to engage with participants and unearth their subjective experiences of supporting end of life care in the home. My research aim and objectives were leaning towards qualitative research method and as a novice researcher, the challenge was deciphering which methodological approach to engage. Patton (2002) usefully offers some wider perspective on research design in stating:

Any given design inevitably reflects some imperfect interplay of resources, capabilities, purposes, possibilities, creativity and personal judgements by the people involved. Research like diplomacy, is the art of the possible. (p.12)

Within the qualitative paradigm, a number of research approaches are offered, through which to view and interpret a phenomenon of interest including but not limited to phenomenology, grounded theory, ethnography and narrative analysis (Parahoo, 2006; Patton, 2002). Each of these approaches has evolved from particular methodological frameworks which in turn have evolved from distinctive disciplinary traditions, thus “making the world visible in different way” (Denzin & Lincoln, 2005, p. 4). Determining the path and design of a research study is less a matter of one approach or method being entirely weak or strong “but rather more or less useful in relation to certain purposes” (Sandelowski, 2000, p. 335). Therefore key considerations or pivot points for determining the path and design of the present study were its purpose and intended audience (Patton, 2002).

The overarching purpose of the research was twofold, firstly to extend existing knowledge of the key conditions under which family carers were able to sustain their care contribution and support of end of life care at home, and secondly, to acknowledge and advance understanding of self identified strengths, resources and skills carers engaged or evolved within this care context (Grande et al., 2009). In terms of the audience, these research findings are intended to be of relevance to policy makers, palliative care service providers and health care professionals supporting end of life care in the community, who collectively commission and provide formal care in this context. It was with both the research purpose and audience in mind that the key decisions concerning the overall research design and methodology were made, with some qualitative approaches being deemed less useful in meeting the aforementioned objectives.

Basic qualitative descriptive (BQD) method as described by Sandelowski (2000), affords a methodology in which interpretation of data is low-inference and confers “no mandate to represent the data in any other terms but their own” (p. 338) as described by participants. In this influential paper Sandelowski, aimed to provide both critique and clarification of BQD as a legitimate methodological approach in health research. In challenging prevailing opinions at the time, Sandelowski sought to encourage a rediscovery of BDQ amongst what she described as the “increasing complexity” and “tyranny of method” in qualitative nursing research (p.334). Sandelowski (2010) clarifies in a recent discussion paper her intention a decade ago was not to imply that BQD eliminates a researcher’s requirement to analyse and interpret data, rather acknowledging “qualitative descriptive research, always requires moving somewhere: that researchers make something of their data” (p. 79).

BQD method as described by Sandelowski (2000) was considered appropriate for the present enquiry on a number of counts. Firstly there seemed a paucity of research on carer identified strengths, resources and skills that enabled them to sustain their caring contribution to end of life care in the home (Grande et al., 2009). BQD method is also deemed conducive to accommodating variation in informal carer perspectives (of varying relationship to the care recipient) and the need to present resulting data in a manner that will influence service development and afford “straight answers to questions of special relevance to practitioners and policy makers” (Sandelowski, 2000, p.337). It was hoped the enquiry would, through inviting participants’ to reflect on their experience, excavate and illuminate aspects of participant resilience in terms of their “ability to withstand and rebound from disruptive life challenges through a process of adapting to adversity, such as providing end-stage care” (Waldrop et al., 2005, p.636). Endeavours to recognise and assess family carer needs and enhance targeted carer supports would benefit from these added perspectives.

3.2.1 Setting

This study was set within the services of one specialist hospice palliative care service located in a region of New Zealand with a resident population of over 42,540 people. This region comprises a high retirement population with census figures for 2006 indicating this area comprised the highest proportion of older people within its population with 16.1% aged over 65 years, compared with 12.3% aged over 65 years for the whole of New Zealand ([name] District Health Board, Health Needs Assessment, Ministry of Health, 2008). This percentage of the region’s population aged over 65 years is projected to peak over the next five years to 21.2 % of the population by 2016. These demographics can be aligned with the global trends outlined in Chapter 2 that suggest ageing populations’ combined with, lengthening illness trajectories and increasing life expectancies will see increased demand for palliative care services in the future (Perreault et al., 2004). Due to the comparatively small population size of the region, the area has not been identified so as to protect privacy of participants.

Patients registered with the HPCS remain linked with their general practice teams and have access to a full compliment of palliative care services including a specialist multidisciplinary palliative care team; a six-bed inpatient hospice unit; a community palliative care nursing team; 24 hour telephone support and on-call nursing service; free hospital equipment loan service and a family (bereavement) support service (FSS). Support packages for personal

care and home help can also be initiated by referral from the HPCS to the patient's choice of one of four independent community support care services.

3.2.2 Participants

All participants were required to have encountered the common experience of being a primary family carer who had supported end of life care and death at home for a terminally ill spouse, family/whānau member or friend. This in itself necessitated that interviews be with bereaved family carers. However, further justification of conducting interviews retrospectively lay in the strong evidence within the literature of altruism amongst carers, where it is recognised they may be hesitant or reluctant to acknowledge their own views or needs above that of the patient, whilst in the caregiver role (Morris & Thomas, 2002; Soothill et al., 2001).

3.2.3 Recruitment

Recruitment of participants was commenced once ethics approval had been obtained as per the recruitment algorithm (Figure 1). Participants were recruited from the FSS register which lists all people currently receiving support from the service including bereaved family or friends of deceased persons' who were previously under the HPCS. A primary family carer was identified from both the deceased patient file and by the palliative care team as "the main person who provided unpaid practical and emotional support to the patient on a regular basis and was in contact with the palliative care team" (Walsh et al., 2007, p. 142). This precluded the assumption being made that the primary family carer was synonymous with next-of-kin, whilst also recognising in some instances it may well be. Purposive sampling techniques endeavoured to capture a broad range of perspectives from family carers who were of varying relationship to the care recipient. This was intended to both acknowledge changing carer demographics described within the literature and extend existing knowledge that, until recently has been predominantly focused on spousal caregivers (Currow et al., 2008; Grande et al., 2009; Payne, 2007; Visser et al., 2010).

Figure 1. Recruitment algorithm

The study sample comprised of six voluntary participants who met the following criteria: minimum age of 18yrs; at least four months post bereavement; well enough physically and mentally to participate and able to give informed consent.

Recruiting bereaved people into research studies presents ethical considerations in terms of recognised emotional vulnerability incurred by the grieving process, however there is lack of consensus in determining how soon to recruit people following bereavement (Buckle, Dwyer, & Jackson, 2010; Parkes, 1995; Rosenblatt, 1995; Steeves, Kahn, Ropka, & Wise, 2001). Diminished competence or decision-making ability in early bereavement may be assumed, yet evolving theories of grief are increasingly recognising the variability inherent in the grief experience, and that society does confer competence in decision-making when many bereaved people are arranging funerals within days of their loss (Buckle et al., 2010).

The minimum time lapse of four months post bereavement was set in consultation with the Family Support Coordinator (FSC)¹ as a respectful amount of time to observe and not intrude on the early stages of an individual's grief. Setting a maximum time interval between the bereavement and interview was not considered necessary. Although some would suggest a prolonged period could negatively impact on participant's recall of events and overall quality of the retrospective data, there is also the counter claim that providing end of life care for a close relative or friend and their subsequent death is a sufficiently salient event to expect reliable recall (Addington-Hall & McPherson, 2001; Visser et al., 2004). The period of bereavement for participants at interview ranged between 8-15 months.

The parameters of the inclusion criteria were to require further clarification due to developing concerns that some potential participants may have been excluded due to the FSS interpreting their role, as needing to perform some level of assessment in terms of participants physical and mental health to participate. Following discussion with my supervisor I clarified with the FSS that unless there was a strong indication that an approach (by phone call) about the study would cause the individual harm and/or they would be incapable of providing informed consent owing to physical or mental debility, then they should not be excluded. I also reinforced the fact that within the recruitment process there were a number of opportunities for individuals to opt out should they wish. This highlighted to me the challenge and importance of taking on and maintaining the role of researcher as opposed to colleague or employee when conducting research in your place of work. Engagement of the FSS as an intermediary in preliminary recruitment was essential to reduce selection bias and a potential conflict of interest, as aside from my education role within the HPCS, I also maintain a small clinical role on a casual basis as an inpatient or community nurse.

A list of 12 eligible participants was collated initially and it was deemed appropriate for the FSS to contact six of them in the first instance then continuing down the list only as required until a sample of six were consented. It was considered unnecessary and potentially unfair to approach a larger number initially on the assumption that some may decline, for if they did not, a process of excluding some would then have to be implemented. Initial phone contact was made by the FSS to ascertain interest in the study and whether potential participants wanted to receive written participant information about the research. It was agreed by both the FSS and I that the phone call inviting participation in the research was to be separate from any

¹ Person with designated oversight of the FSS

planned FSS bereavement support phone calls. In practice this meant the FSS would make the phone call usually one week following their planned FSS contact. This was deemed an important step in both maintaining integrity of the FSS and avoiding any connotation that ongoing FSS support was in anyway linked with research participation.

Those who expressed interest in the study were posted a covering letter inviting participation (Appendix 1), study information sheet (Appendix 2) and informed consent form (Appendix 3). I then made phone contact one week later to talk through the information sheet and discuss/clarify study aims, purpose, participation and informed consent. Although not taken up by anyone, following these discussions potential participants were offered further time to consider and/or discuss the study with family/whānau before reaching their final decision. Upon obtaining verbal consent to enter the study, a date time and venue of the interview was negotiated and arrangements for signing of informed consent confirmed.

Of these initial six people, one who was the wife of a deceased gentleman, indicated in my follow up phone call that after reading the study information sheet (Appendix 2) she considered the primary family carer for her husband was her daughter, who supported them both during his illness and in the final weeks at home. Indeed she believed her husband's death at home would not have been possible without her daughter's input. She had shared the study information with her daughter and on this basis her preference was for me to approach her daughter. Whilst I had not anticipated this situation and perhaps the suggestion lay outside the intended recruitment process outlined previously, on consideration, the daughter did fit the entry criteria. On balance it was deemed this deviation to the recruitment process outlined earlier, was justified and aligned with the intent to obtaining maximum heterogeneity of the sample.

3.2.4 Data collection

Data were collected by way of semi-structured interviews with each participant of approximately one to one and a half hour duration using an interview schedule (Appendix 4). The interview schedule served to both guide me as a novice researcher through what was a sensitive enquiry and ensure identified research questions were addressed within the allotted interview time (Patton, 2002). As the interviewer and thus the 'data collecting instrument' I was compelled to employ strategies to underpin both my credibility as a researcher and the rigour of the interview process (Patton, 2002; Parahoo, 2006). In part, the quality of the data

collected was reliant on my skill and experience to put the participant at ease through use of effective communication skills and my experience in interview technique, which in reality was evolving and improved as the study progressed (Appleton, 1995).

Establishing a collaborative partnership with participants at the beginning of the interview was important in ensuring the data obtained would be “useful, reliable and authentic” (Patton, 2002, p. 384). To some degree establishing rapport may have been assisted by the fact that I had met all but one participant prior to interview. Two participants were nurses employed within local health services external to the HPCS and knew of me in my role as PNE for the HPCS. Another participant had met me within the community (external to my professional role) and of the six participants, three had encountered me during home visits as a community palliative care nurse. It is important to clarify that my role as a community palliative care nurse is a minor one, occurring on an intermittent and casual basis and all these encounters with participants had occurred before this research project was devised. However, I was aware of potential bias in terms of how their previous knowledge of me as either a nurse, a member of the HSPC service, or informally, may influence their participation and candour in the interview. I endeavoured to counter this by reaffirming the focus of the research and my role as researcher and their rights as study participants, during all phone contacts and at the beginning of interviews.

I was also aware of potential bias through the interplay of my researcher role throughout the study, and professional background as a palliative care nurse. Dual tension, in terms of strength and weakness, lay in my professional knowledge allowing on one hand “to be an insider to the milieu” which participants described (Weiss, 1995, p. 137), while also presenting potential to infer a selective perception or interpretation of participant’s subjective descriptions (Patton, 2002). Reducing this potential bias has been by way of maintaining a reflexive approach throughout the study, which is defined as a “continuous process of reflection by the researcher on her own values, preconceptions, behaviour or presence and those of the respondents, which will affect the interpretations of responses.” (Parahoo, 2006, p. 326)

In practice this included measures such as ensuring myself adequate rest and ample time to prepare prior to conducting each interview to focus on my role as researcher and mentally positioning myself as the ‘privileged enquirer’ working in partnership with each participant

(Weiss, 1994). Owing to the sensitive nature of the enquiry, I had anticipated the interviews could be emotionally draining for both participants and myself and ensured I conducted no more than one interview a day. The duration of each interview varied between the shortest of 69 minutes and the longest being 82 minutes. It was my experience that the proposed 60-90 minute interview time was long enough to address the research questions and sustain my total focus on what participants were saying.

I also observed a reflective period immediately following each interview whilst the interview and initial insights were fresh, where I checked the quality of the audio recording and documented written field notes of the interview setting, nuances expressed by participants, my observations, and critical reflection the “shared experiences of researcher and participants” (Green et al., 2007, p.547). This was important time in terms of my evolving interview technique and the field notes provided a base and context for recall later during data analysis processes (Patton, 2002).

The interview setting was nominated by the participant to be the most accessible, and/or comfortable place for them, where they felt able to talk freely about the topics on the schedule. Two participants chose for their interview to be conducted in their home whilst the remaining four opted to be interviewed in a quiet interview room at the hospice. Prior to commencement of interviews it was re-confirmed with each participant that they had read and understood the study information in relation to: intended areas of questioning; the process should they wish to suspend the interview at any point if uncomfortable or upset and in need of time to recover; access to grief and loss support if required; and confirmation they were happy to proceed with the interview.

Pausing of interviews did occur at request of participants for reasons of emotional upset, interruptions from family in the case of one home based interview and on three occasions, recounting of unpleasant events participants were unsure they wanted included in the research. In the latter situation I would allow the participant opportunity to discuss the event off tape and to consider the option of offering a summary of the event when the interview and recording was recommenced. In the three interviews where this occurred, two participants chose this option, the third elected not to expand further on the event. Managing these events in this manner was in alignment with the ethos of ongoing consent (Richards & Schwartz,

2002), but also allowing opportunity for inclusion of data that may later prove significant in terms of the overall experience of family carers supporting end of life care in the home.

For interviews conducted at the hospice, I ensured drinks of water and tissues were readily available for participants. During the interview process, participants' were encouraged to expand on their own perspectives and experience through the use of open-ended questions and rewording of questions as necessary to minimize ambiguity or misinterpretation by participants (Appleton, 1995). The inclusion of open-ended questions to which participant responses were sought was to primarily allow me to "understand and capture the point of view of other people" (Patton, 2002, p. 21). It was also my observation that in order to obtain full descriptions of participant experiences, there was a need to allow a degree of 'flow' to participant accounts by minimising interruptions and accepting that questions would not always be addressed in the order they appeared on the interview schedule. Weiss (1995) acknowledges this as good practice in terms of "following the respondents associations so long as they remain within the interview's frame" (p. 81). The six interviews were completed over a three week period and all were audiotaped and later transcribed verbatim by an independent professional transcriber.

3.2.5 Interview schedule

Questions on the interview schedule were divided into nine categories that had been identified and formulated following review of current literature and in consultation with colleagues within the palliative care field. A draft interview schedule was devised and reviewed by members of the FSS for their critique as to whether the identified question categories would inform the identified study objectives and overarching research aim outlined at the beginning of this chapter. Following this consultation and further amendments a final draft of the interview schedule (Appendix 4) was completed, of which the question categories and rationale are outlined below (Table 1). In all question categories, except the first, participants were asked to focus their responses on the period of care from the point of referral to the HPCS through until the care recipient's death at home. This measure was intended to focus the enquiry towards care giving at end of life.

Table 1. Interview schedule question categories

Question category	Rationale
1. Demographics	Socio demographic data of participant and patient. Building rapport with participant and understanding of how they perceived their caring role. Impact of care recipients preferences for end of life care, if known, on role supporting care at home.
2. Caring activities	Exploring caring activities or support provided by the carer to the patient. How any concurrent roles or responsibilities were managed or balanced at the time.
3. Informational supports	Identifying informational supports, access and timeliness.
4. Practical supports	Exploring practical supports & information, sources, access and timeliness
5. Emotional supports	Forms of emotional support, sources, access and timeliness
6. Wider support networks	Informal/unpaid support networks, sources and value placed on these by participant
7. Self-identified skills and strengths	To illuminate existing skill sets and strengths that may have been foundational to fulfilling role and contributed to participant resilience during this time.
8. Carer needs	How participants perceived their own emotional and physical needs during this time and whether or not they felt able to express and/or have them met and by whom.
9. Impact of caring experience on life at present time.	Reflective account of caring experience by participant and what they consider important for health professionals to understand of the reality of informal end of life care in the home.

3.3 Treaty of Waitangi considerations and obligations

Because Maori are disproportionately represented in negative health statistics and outcomes within New Zealand, it is essential to recognise and acknowledge that all health research in New Zealand is of relevance to Maori (Health Research Council of New Zealand, 2008). In planning this study the principals of protection, participation and partnership were upheld through consultation processes facilitated by the hospice kaumatua. A Maori Research Consultant and Maori Advisor nominated by the kaumatua, both reviewed the research proposal and met with me to discuss the study. They deemed that appropriate strategies to address the needs of potential Maori participants had been considered and incorporated into the study design. It was however recognised and acknowledged that the recruitment criteria may not in this instance elicit Maori participants on the basis that all recent Maori patients who had been through the HPCS had died within the hospice or an inpatient setting. It was

jointly acknowledged this may be future collaborative work to explore and outside the parameters of the current study.

It was offered that should any participants identify as Maori, the Maori Research Consultant would be available to facilitate the support and presence of a whānau ora support worker at interview to address any issues that arise and provide support for myself the principal investigator as I am pakeha. As it transpired, one participant at commencement their interview identified their ethnicity as part New Zealand Maori and part Pakeha, it was ascertained at this point they were comfortable to proceed with the interview without whānau ora support. In retrospect it is acknowledged I should have ascertained the ethnicity of participants in my first phone contact prior to the interview, so that if the presence of a whānau ora support person was requested this could be arranged ahead of time.

3.4 Ethical considerations

Ethical approval for this study was granted by the appropriate regional Ethics Committee (Appendix 6 & Appendix 7). In planning and carrying out qualitative research into health and healthcare it is essential to consider ethical issues that may pose potential risks to participants and work towards minimizing these risks (Richards & Schwartz, 2002). Key concerns in this research were that anonymity and confidentiality of participants were protected and that there was adequate exchange of information about the research to allow them to make an informed decision to enter the study (Tolich, 2001). Within the context of healthcare research, self determination affords prospective participants' the right to ask questions, refuse to give information and voluntarily choose whether or not to participate without the risk of adverse consequences (Polit & Beck, 2006).

3.4.1 Informed consent

Informed, signed consent was obtained from all participants (Appendix 3). An information sheet (Appendix 2) posted to eligible participants outlined the study purpose, focus of questioning, and intended use of study results, efforts of anonymisation and potential benefits and risks of their participation. Given the unpredictable, evolving nature of qualitative research it is advocated by some researchers that consent is treated as a process open to review as oppose to a one-off event (Parahoo, 2006; Richards & Schwartz, 2002). Therefore the consenting process devised, allowed both time and opportunity for participants to consider the study information sheet (Appendix 2) and discuss questions with the principal investigator

and advocated that participants consult with family/whānau or friends if desired (Richards & Schwartz, 2002). Once consent was signed participants were given a copy of the consent form that affirmed their rights, including the right to withdraw from the study at anytime without providing a reason or risk to them of any adverse consequences. The consent form (Appendix 3) also outlined their right to withdraw their interview transcript from the research up until the point they had approved it after reading and/or edited its content.

3.4.2 Privacy considerations

In this study the data collection process was designed to maintain confidentiality including non-identification of the region in which the study is conducted. I conducted the audio-taped interviews, in which only the participant's first name was referred to in the interview. On transcribing names of persons and places were omitted and indicated accordingly in the transcripts as [name] or [place]. The independent transcriber was required to sign a confidentiality agreement (Appendix 5), as they were privy to the participants' first names and other potential identifying information through the tapes. Only I retained a master copy of the participants' names and related demographic data, which remained stored in a locked facility in my office as per the requirements of ethics approval. Any electronic files and audio tapes remain password protected. Informed consent from participants' permits me to retain this data as primary source material for future related studies that obtain ethical approval from a Health and Disability Ethics Committee and in accordance with Victoria University of Wellington regulations.

3.4.3 Minimising risks

Other potential risks to participants in this study not previously outlined included: potential for emotional upset; failure to recount participant accounts accurately; and impact on participant's personal time required for interview. Steps taken to minimise these risks are outlined below.

Because the topic of enquiry had potential to cause upset for bereaved participants, previous measures outlined under data collection relating to ongoing consent and stopping of interviews if participants became upset, were observed. Participants were also invited to attend the interview with a support person of their choosing if so desired. This option was only taken up by one participant who attended with a close friend. Also, at commencement of the interview participants were reminded of the availability of free independent counselling

upon request through the FSS. When interviewing bereaved individuals the potential to induce sadness or grief is ever present but it is also argued, in this context, qualitative researchers are neither causing nor inducing emotional pain but bearing witness to pain of loss that is already there (Buckle, Dwyer, & Jackson, 2010; Cook, 2001). This was certainly my experience as the nature of the enquiry predictably stirred emotions in most participants, and so too this was anticipated by them:

Rather we ask about experiences that are often shrouded in sadness and we empathetically listen to the person, even if the message is accompanied by tears. Bereaved participants almost always expect the discussion of their losses to be painful, but are not deterred by this awareness. (Buckle et al., 2010, p. 118)

There is also recognition that alongside potential vulnerability, the opportunity to be involved in research interviews can offer bereaved participants a degree of catharsis as they reflect upon and articulate their experiences (Buckle et al., 2010; Drury, Francis, & Chapman, 2007). Buckle et al. (2010) maintain this is determined by the quality of the interpersonal relationship between researcher and participant in terms of “empathy, collaboration and empowerment” (p. 210), which at best can offer a therapeutic quality to the interchange. Drury et al. (2007) advocate, where researchers are well versed in active listening and clear boundaries within the interview process, participants may simply appreciate having the opportunity to tell their story to a willing and attentive listener.

Within the present study evidence of the therapeutic nature of qualitative interviews was revealed in the unsolicited comments from participants when contacted post interview. Two related they valued and enjoyed the interview process as an opportunity to reflect upon and acknowledge their caring experience. Conversely one participant reported he ‘lost the plot’ two days following his interview and became tearful and upset. He received immediate solace from close friends who, through prayer and spiritual support, provided him reassurance in his grief. He declined the offer of free independent counselling available to him under the approved ethics provisions outlined earlier.

Accurate recounting of participant experiences was enhanced through audio-taping of interviews that were professionally transcribed verbatim and brief interview field notes I had made following each interview as outlined under data collection. Before content analysis was performed, typed transcripts were returned to participants for viewing to confirm accuracy of

their accounts and allow opportunity for them to indicate any areas they would not like revealed for reasons of privacy. All participants returned and approved their transcripts, with no requests for editing and only two participants highlighting minor spelling errors for correction. Finally endeavours to minimise the impact on participants' personal time was primarily by way of conducting the interviews on a day, time and location most convenient to them.

3.5 Credibility and transferability

Within the qualitative paradigm, credibility of study findings pertains to both confidence in the truth or trustworthiness of the data collected and its interpretation and requires the researcher to incorporate various strategies within the study design that demonstrate and enhance credibility (Patton, 2002; Polit & Beck, 2006). Data collected within this study included the interview audiotapes, interview transcripts that had been professionally transcribed verbatim and the researcher's field notes written post (each) interview.

In addition to guidance throughout the study by the thesis supervisor, I received peer debriefing within one or two days of each interview with the Family Support Coordinator (FSC) who acted as external check on the interviewing process (Polit & Beck, 2006). The FSC is a registered nurse who holds both a Postgraduate Diploma in Community and Child Health and Certificate in Grief Support. Alongside these qualifications the FSC has extensive experience working with and supporting bereaved family, partners or friends and bearing witness to numerous stories and experiences of family carers who have supported the dying at home and the subsequent impact the experience has had on them. These reflective sessions enabled me to develop interview technique and enhanced ability to enter into and 'hear' the participant's perspective and capture quality data (Patton, 2002). Care was taken by myself during each debrief, not to identify the participant interviewed.

Transferability of the study findings to other palliative care contexts is ultimately reliant on my ability to provide full and thorough description of the chosen research setting and processes throughout the study, so the reader can draw similarities and congruence to their practice experience and/or setting (Polit & Beck, 2006). Also in reporting the findings of the present study, extrapolations will be offered as "modest speculations on the likely applicability of findings to other situations under similar, but not identical, conditions" (Patton, 2002, p. 584). Patton further advocates extrapolations are useful "when based on

information-rich samples and designs, that is, studies that produce relevant information carefully targeted to specific concerns about the present and the future” (p. 584).

3.6 Data analysis

As previously indicated, data analysis was commenced following each interview with my recording of written field notes. Interviews were audiotaped and later professionally transcribed verbatim to typed format for qualitative content analysis. The six interview audiotapes produced a total of 185 pages of typed transcript and 10,922 lines of typed dialogue to be coded and analysed.

The manual process employed to simplify and make sense of the data is described below and comprised a process of qualitative content analysis involving four key steps of “identifying, coding, categorising, classifying and labelling the primary patterns in the data” (Patton, 2001, p. 463). Sandelowski (2000) maintains that whilst qualitative content analysis involves a process of “counting responses and the numbers of participants in each response category”, the final results should be more than a “quasi-statistical rendering of the data, but rather a description of the patterns or regularities in the data that have, in part, been discovered and then confirmed by counting” (p. 338). Understanding the meanings in the data based on a range of accounts is the key emphasis of descriptive studies (Green et al., 2007). The report of the findings in Chapter 4, comprises a descriptive summary of the key themes and patterns derived from the data that were in turn “organised in a way which best fits the data” (Sandelowski, 2000, p. 339).

Formal analysis of the approved transcripts began with reading each individually whilst listening to the interview audio-tape to both check the transcripts for accuracy and begin the process of familiarising myself with the data. This was an important step as although I had conducted all of the interviews, I had not transcribed them owing to the level of transcription required and time constraints precluding me from doing this. Alongside reading each transcript I reviewed my interview field notes which endeavoured to capture details of the interview context adding to both the depth and detail of the data immersion process (Green et al., 2007).

In a second reading of each interview transcript, summaries were devised whereby the documented responses to each of the nine question categories were identified throughout the

transcript and collated onto a simple interview summary template containing nine sections representing the nine question categories. The resulting six interview summary templates were cut into the nine question categories, with each section taped to a large corresponding summary sheet, of which there were nine, one for each question category. This began the process of comparing and identifying a coding scheme for the interview transcripts.

Once the coding strategy was developed, formal coding of transcripts began with shorthand codes applied directly in the margins of relevant data passages (Patton, 2002). Once coded, transcripts were cut up with data organised into nine question category files. Some overlap was evident whereby data could be coded to more than one category file and so a tenth file was assigned for these responses. The tenth file was later reviewed against the full passages of complete interview transcripts to reaffirm the context of the response and from this vantage point treated in one of two ways. Either they were assigned to the category file their content most prominently conveyed or if the data was essentially insignificant in terms of failing to “increase or deepen understanding of the phenomenon studied” (Patton, 2002, p. 467), then it was deemed redundant and removed from further analysis.

These collective processes demonstrate the essentially reflexive and interactive nature of qualitative content analysis whereby the researcher reads the data to analyse and discover through inductive reasoning prominent patterns including commonalities or natural variation and repeatedly returns to the data with new insights that modify further treatment of the data (Polit & Beck, 2006; Sandelowski, 2000). Classifying and labelling of primary patterns in the data was achieved by reviewing the content of each file and creating a visual framework, in the form of a mind map, for each file as a way to organise and describe the emerging patterns or themes in the data (Sandelowski, 2000).

At this point I met with the FSC who acting as a second observer, had independently read two randomly selected de-identified transcripts and also utilised interview summary templates to group data into the nine question categories and identify major themes and patterns present in the transcripts (Patton, 2002). We were able to compare these interpretations with those represented in the mind maps and verify compatibility between the categories identified within the data and prominent patterns or themes emerging (Patton, 2002). These measures were collectively intended to counter the “intrinsic bias that comes from single-method, single observer and single theory studies” (Denzin, 1989, p. 313, cited in Polit & Beck, 2006), and

ensure an accurate and complete portrait of the family carers context, perceptions and experience was presented. Further steps taken to reduce data followed consultation with my supervisor and further reading that enhanced my understanding of qualitative interpretation, in particular:

Qualitative content analysis moves farther into the domain of interpretation than quantitative content analysis in that there is an effort to understand not only the manifest (e.g., frequencies and means), but also the latent content of data. (Sandelowski, 2000, p. 338)

My initial efforts to reduce this descriptive data had been guarded and my interpretation rudimentary until my understanding and confidence to move deeper into the data was encouraged by my supervisor and supported through further reading. From this vantage point, key themes and sub themes were identified and are reported in the following chapter.

Chapter 4. Findings

4.1 Introduction

The purpose of this study was to explore and describe end of life care in the home from the perspective of family carers to reveal the nature of their care contribution and conditions under which they were able to sustain their role. In particular the enquiry sought to reveal self-identified strengths and skills utilised by participants from the time patients were referred to the HPCS until their death at home and the formal (paid) and informal (unpaid) support networks engaged and/or experienced by participants over that time.

This chapter begins with an overview of participant and patient demographics, and participant perspectives of their caring role supporting end of life care at home. A summary will follow of the key themes and primary patterns derived from the data relating to the nature and experience of supports engaged and experienced by participants (Figure 2). In order to protect the confidentiality of both participants and the patients they supported, pseudonyms have been assigned and any potentially identifying data including for example, place names have been withheld and indicated in brackets [place name].

4.2 Overview of participant and patient demographics

Six participants were recruited to the study, each of whom was a primary family carer for a terminally ill relative up to and including their death at home. Familial relationships to the person(s) that died varied across the sample group with one participant being a sibling, two were wives, two were daughters of whom one supported her father and the other her mother, and the remaining participant was a male who cared for his wife. Length of time since bereavement at time of interview ranged between eight and 15 months. Ethnicity of all but one participant was New Zealand (NZ) European with the remaining participant identifying herself as both Maori NZ and Pakeha. At time of bereavement, participant ages ranged from 45-65 years (Table 2)

Table 2: Participant demographics

Participant	Gender (M/F)	Age (years)	Ethnicity	Relationship to the person that died	Length of bereavement at interview (months)
Mary	F	65	Maori NZ / Pakeha	Sister	12
Geoff	M	62	NZ European	Husband	8
Kate	F	53	NZ European	Daughter	14
Diane	F	64	NZ European	Wife	15
Jane	F	61	NZ European	Wife	10
Fiona	F	45	NZ European	Daughter	14

Of the recipients of care, five had a primary diagnosis of cancer; two women with breast cancer, two men with prostate cancer and one woman had a brain tumour (Table 3). The remaining patient had a diagnosis of Parkinson disease compounded in the final 12 months of his life with diagnosis of myelofibrosis² which was the key prompt for his referral to the HPCS. This gentleman was receiving monthly blood transfusions at the time of his hospice referral and these continued via the HPCS well into his final year of life. The illness trajectories of these patients varied in duration ranging, when taken from the point of illness diagnosis to the patient's death, between four months to 22 years. For most participant's this represented significant periods of time (years) in which they were assimilating, learning and adjusting to a revised role and providing increasing support for the patient. For the sixth patient Sandra, the period of time from diagnosis to death was a brief four months, in which time her physical functioning rapidly deteriorated and her daughter quickly assumed total and intensive 24 hour support of her mother's care. The length of time these patients were on the HPCS programme varied from three and a half to 13 months.

² The replacement of bone marrow with fibrous tissue. The condition may be associated with anaemia, thrombocytopenia and other abnormalities in blood cell formation.

Table 3: Patient demographics

Participant	Patient	Gender	Time from diagnosis to death (years)	Primary Diagnosis(s)	Time on HPCS programme (months)
Mary	Joan	Female	11	Ca Breast	4.5
Geoff	Brenda	Female	12	Ca Breast	13
Kate	John	Male	1	Ca Prostate	13
Diane	Barry	Male	3	Ca Prostate	5
Jane	Richard	Male	22	Parkinson disease/ Myelofibrosis	12
Fiona	Sandra	Female	< 1	Brain Tumour	3.5

Uptake of practical supports available whilst on the HPCS programme is summarised alongside participant employment and residential status whilst in caring role (Table 4). Hospice equipment loan was utilised by all participants predominantly in the form of hospital beds, wheelchairs and other equipment to promote mobility and comfort of the patient in the home. Overwhelmingly participants appreciated the availability of this equipment and perceived its use as essential to enabling the patient remain at the home.

Formal carers were engaged to support physical care of the patient in the home by all but one participant (Diane) for whom a family member was able to provide this support in the final week of her husband's life. For Jane, the formal carer who had supported her mother's care for over three months withdrew from the role a week prior to her death. For Jane this event challenged her coping, and was compounded upon learning that alternative volunteer support the HPCS had indicated would be available was unable to be secured at the time. Combined these events almost caused her to default on continuing care at home. Exhausted and tired it was only with the timely arrival of her brother from overseas to support care, that she felt buoyed and able to continue care of her mother at home through the final week. Hospice inpatient respite was utilised by half of the patient group who were on the HSPC programme between 12-13 months, whilst the remainder who were on the HSPC programme from between 3.5-5 months did not access this service.

Table 4: Practical support uptake whilst on HPCS, participant employment & residential status

Participant	Hospice equipment loan utilised?	Formal carers assisting nursing care at home?	Hospice IPU respite utilised?	Maintained employment whilst caring?	Shared residence with patient prior to carer role?
Mary	Yes	Yes	No	No Resigned job to support care	Yes
Geoff	Yes	Yes	Yes	Yes Supportive employer	Yes
Kate	Yes	Yes	No	Yes Supportive employer	No Lived local to patient
Diane	Yes	No Grand daughter a nurse, supported care last week	Yes	No Not working at time	Yes
Jane	Yes	Yes	Yes Long-term, in home established prior to HPCS	Yes Supportive employer	Yes
Fiona	Yes	Yes Carer resigned, brother supported care last week	No	No Self employed, deferred contracts to support care	No Patient moved from another region to live with participant

Figure 2 Summary diagram of findings

4.3 Perception and acquisition of caring role

Participants shared a range of perspectives and experiences of both their caring role and the supports they encountered when providing informal care to their terminally ill relative. At interview whilst I addressed participants in their role as an ‘informal’ carer, the term seemed somewhat redundant and imposed as it was not echoed in the responses or vocabulary of any participants in referring to themselves. Although up until this point its intended use in this study, was purely as a descriptor to delineate between participants and formal (paid) carers, subsequent reflection on participant accounts and discussions with palliative colleagues prompted me to reconstitute the term ‘informal’ carer with ‘family’ carer. Reference to ‘family carer’ avoids any potential inference of a hierarchy whereby ‘informal’ could be interpreted to imply ‘less than’ formal carers and ‘family’ is intended to encompass varied social and cultural constructs, beyond shared biological, social or legal ties (Payne, 2004). The impersonal and somewhat detached term ‘informal carer’ was to prove incongruent with

the relationships described and held between participants and patients in the present study. It was therefore deemed that 'family carer' more ably and respectfully represented this participant group and should be subsequently utilised.

Large sections of transcriptions are presented in this findings chapter as these reveal, through the words of participants, the poignancy of their care giving experiences. For most, transition to the role of family carer and assimilation of added tasks and responsibilities as their relative's illness progressed was gradual, foreseeable and well embedded upon introduction to the HPCS:

And as the year went on she got physically less able to do anything, she got physically less able to lux (vacuum) the floors, she physically couldn't stand at the sink any longer than about five minutes to wash the dishes or scrub the potatoes and then I realised then that it was my duty to, not my duty, my right to take over the cooking...even though I was doing long hours at work.....I just knew then it was time for me just to take over everything she was doing and let her have some peace for the last months of her life really. Geoff (husband)

For some their caring role was perceived as an extension of existing familial bonds:

Well it's a twin thing. And my role, as I've seen it, has always been to look after her...So I had always felt that I had a role...and no doubt, she felt that towards me as well, that I had a role of looking after her. So it was perfectly natural for me to assume that I would look after her when she became ill. Mary (sister)

Being responsive to changing needs of the patient was increasingly a central pivot point described by many participants:

Well to me, it was a day-to-day thing, I was very sensitive of whatever it was on that day. Some days he was quite good, and he'd just want me to be pottering with him, and other days he'd be miserable, and he just needed me...just to have that support person round, and so that was what I had to do that day. Diane (wife)

I was at her beck and call for the last two years, whatever she wanted, I bloody well done. Geoff (husband)

Supporting her father's care at home carried a dual commitment for one participant, to her mother, who increasingly relied upon her daughter's knowledge and skills as a health professional at this time:

Well I guess my role was very much influenced a) I was his daughter but b) being a registered nurse as well gave it quite a different slant on things and for that reason, my mother did perhaps devolve more responsibility to me than maybe in another situation where other children didn't have those skills. She saw that was what I did, even though I'm not in acute nursing at the moment, but that was what I did. I knew the (health) system, and that certainly does help, when you know contacts, you know people, you know roughly how the system works. Kate (daughter)

In the case of one participant however, her induction to the role of family carer was rapid and simultaneous to her mother's referral to the HPCS. A sudden immersion into providing 24 hour nursing care upon her mother's discharge from hospital followed:

I guess I was her primary, I was full-time... 24 hour primary caregiver I tended to all her medical needs. I didn't do her intimate personal needs because we had someone who came in and did the showering. I helped her with her toileting and then as she deteriorated, I did more and more and more, helping with enemas and did the meds (medications) and did the lot...She was very high needs...She couldn't get out of bed without help, she couldn't dress herself without help. Fiona (daughter)

Under no illusions of what would be required, her commitment to support her mother at this time was absolute, with her life and home adjusted accordingly:

When I realised she was coming here, and I realised the level of care she would [need] and I decided that - work you can do any time. You can only have one time with your Mum, and this was going to be special. So I just quit all my jobs and said, "No, that's it, can't do this anymore", quit everything and said, "No this is what I am going to do." Fiona(daughter)

For Jane, introduction to the HPCS in her husband's final year of life was a welcome and important support. However for her this only formed part of a much bigger picture in terms of her extensive supportive role that had spanned more than two decades:

When he came under the hospice, the hospice came as another step in the ladder, I suppose you could say, because already we'd gone through this quiet decline, more

increase in support...like washing his clothes. I used to be always so careful about washing his clothes everyday, because he used to mess when he was eating. Um I changed the style he had, so that it was easier for him to get his trousers up and down himself, because he wasn't able to do up buttons, or hooks or anything like that, because of his decreasing dexterity. Jane (wife)

Beyond acquisition of their supportive role, two key sub-themes emerged from the data pertaining to what underpinned and motivated participants at this time: giving back to the dying person and facilitating preferences (Figure 2).

4.3.1 Giving back to the dying person

Common to all participants was a strong expression of love and reciprocity towards the patient that transcended any perceived physical or emotional hardship that accompanied their devotion and sustained their commitment over time. For one participant, caring for his wife was an opportunity to repay the commitment and love she had shown him throughout their marriage, maintaining their home and caring for their children many times alone, when his work took him away for extended periods:

Because she had done every single thing that I had wanted done, she done for me for 34 years so why couldn't I do something for her for too...So it was my turn to look after her, and there was no questions ever asked, never say that I wasn't going to. Geoff (husband)

Similarly a daughter expresses her core motivation:

I think the most important one is the love for my mother. Because I loved her absolutely totally and completely, which meant I would have done anything for her. Fiona (daughter)

Being able to contribute towards her father's end of life care at home, as well as being an expression of love, provided a buffer to a daughter's concurrent feelings of helplessness:

But um you know I felt quite proud that we had been able to do that for Dad. I felt that it was... I couldn't take away his illness. I felt that he was being incredibly robbed of life um even though he was 81..., um that this was yeah kind of the least we could do. You know he'd been a very good father to three, I've got two siblings and um yeah I felt that that's what I wanted to be able to do for him. Kate (daughter)

A wife's commitment to her husband's care was expressed purely and simply:

You just do it. You just do it. And when it's...you don't even think about what you have to do when it's somebody you really love. And you just...it just happens. Diane (wife)

Important to acknowledge, Jane had supported her husband who had chronic illness for 22 years. Her enduring commitment to support him did however reach a critical point a year before he died. For a time she succumbed to suicidal thoughts in response to news her husband was now dependant on regular blood transfusions due to failing bone marrow and a diagnosis of myelofibrosis:

I started the grieving process big time, I feel, because I started to think, well what's going to happen to me when Richard dies?, and then I was thinking about taking my own life. And then it got to the stage where I was um [with emotion] not thinking about when he died, it was about when I was going to do it. I planned what I was going to do. Jane (wife)

A minor omission to some, proved to be one burden too many for Jane and a significant turning point. Well versed in help-seeking for her husband, Jane was now to apply those skills to herself:

Then one day, I had to bring Richard up here (to the hospital) for more blood tests and I snapped at a staff member in the laboratory... and I realised then that something wasn't right for me. And I took Richard home, didn't even let him have the blood test. What happened was the hospice hadn't provided the form for Richard to have the cross matching before he had the next (transfusion) in March. It was all too much for me. So I went to the doctor, and told him what I was doing. He made me promise I wouldn't jump because I was planning on jumping off a bridge [with emotion] and he got me involved in the SMART³ programme and I went, went to that yeah... and I did accept help from him and started on anti depressants, and I went to the gym, went for some massage and a few different things that they the SMART programme offered. So that was one very good thing for me. I yeah [sigh]. It was not an easy time for me. Jane (wife)

³ Community based non-residential mental health support programme

Specific mention was made by half of the participants of increasingly intense feelings of wanting to be with the patient especially towards the end of their illness. For Mary, sharing both her home with her family and time with her sister, caused some tensions and a need to adjust:

Yeah. So I had to...really had to um back off a wee bit from being, you know, just a little bit prickly, and letting them...letting them have access and spend time with Joan as well. Because you know, they were going through the same thing... So I had to pull back a bit, at a time when it (relationship) was really very strong. Mary (sister)

For Geoff, when his wife was in hospice for respite the separation was hard and he would visit at least three times per day:

It (respite) had its own challenges, because I didn't really want to be away from her at that time. If she was fit and able um, and looked after herself, even though she was in hospice, I could have just gone to Australia or something. But a few years ago I would have gone shearing or I would have gone truck driving for three or four days and say "Are you alright love?" But as she got sick, and I knew wasn't long left, I (sigh) um I just couldn't stay away. You know, I just could not stay away. And I think emotionally, she couldn't handle me being away. Geoff (husband)

Similarly, as death approached, the urge to maintain vigil and stay close by the patient became strong and delegating care to others could prove difficult:

And even when like my sister had a turn sleeping (over) and I can just remember I just kept waking up all the time. And um and I...we'd come out and sit there and talk with her for a wee while. And she'd say, "Look, this is your night off. Go and sleep." But yeah, it was the letting go. You kind of get immersed in it that you can't let go. And so you're in this kind of heightened, awareness thing...you're listening for every breath, and you know, the little flash of the syringe driver, and you know, all that sort of stuff...looking back, it all just seemed quite a spaced-out kind of time, almost. Kate (daughter)

As these transcript excerpts illustrate, all participants within the sample group held positive and close relationships with their relative. Strong expressions of love and reciprocity were prominent in all accounts, so too participant awareness of the significant role and life event they had experienced.

4.3.2 Facilitating preferences

Most participants recollected conversations with their relative that clearly communicated their preference to be cared for at home. The timing of these conversations varied with some occurring more readily towards the end of the illness, but in some cases these conversations happened much earlier on in the illness trajectory. For Mary, her twin sister's acceptance of referral to the HPCS was based upon learning that the service could support both her care and her sister at home:

Joan had actually put off wanting [referral]...because her main fear was that she would have to leave home. She thought that if she went under care of the hospice, she would have to come here [hospice] and not be at home. And she said to me once that [she] didn't want me to get so run down and tired that she would have to, as she put it, go away from home. And I just said to her "Joan, you'll never go away from home unless it's a medical emergency"...And I can't remember who it was, but one of your nurses came up and she went in and spoke with her as well and told her then that everything would be provided to ensure that she could stay at home. Mary (sister)

Geoff revealed that conversations with his wife were preceded two years earlier by their decision, upon recurrence of her cancer, to purchase a suitable home in which he would be able to nurse her as her illness progressed. Subsequent conversations came towards the end of her illness, were brief and conclusive:

The only discussion was that she said, "I would like to die at home." And I said, "Well you're not dying anywhere else." It's just as simple as that. Geoff (husband)

Kate determined her father's wish to be cared for at home, less than a fortnight before his death, during a conversation prior to his discharge home from hospital:

I do remember talking about it to Dad. Um, he did say to me that...because he was fearful when he knew he was getting sicker and sicker, er that he might not get home, "No I don't think I'll get home again," was what he said to me. And I said then, I said, "Well, I would like to bring you home. Do you want to come home?" And I can just remember him now holding my hand, he often used to hold my hand when I, you know, talked to him, and he said, "Yes, I would like that." And so- um I don't think my mother was there at the time but um I did have this discussion with her and I did say that I thought that this was what Dad wanted. Kate (daughter)

Whilst her father's wish was aligned with her own, Kate felt that for her mother, the preference may have been his admission to the hospice for terminal care. However any doubts or concerns generated by this were quickly dispelled, the day he arrived home:

I mean the day we bought Dad home, and just got him, it was a lovely sunny day, and just got him all set up, and had him sitting...we just sat him in the lazyboy (chair), and the sun was just streaming through the ranch slider um door...And he just said, "Oh". He put his um head back and closed his eyes, and he smiled, and he said, "Oh, I just so wanted to feel the sun on my face." And that's when I knew we had done the right thing... the house was his, it smelt like home, and it was home...and that for me confirmed that yeah, that you know, I was so happy to see him just relaxed, and have the warmth. Kate (daughter)

For Diane, the decision to nurse her husband at home was informed by both conversations they had and her understanding of his constant desire to be at home:

He was a home person. As I said before, he used to be homesick, even on holiday. He had two nights in the hospice, through this...when they were changing treatments and things. Not a thing wrong with the hospice. But he was always wanting to come home. Even one night when the nurses wanted to keep him for another night, to give me a rest, and it got to about seven o'clock, and I got this ring from the nice nurse who said, 'I've got a message from Barry to say, could his bride please come and get him'. So I did. Because I always felt, well you know, I may need him to be there at the end. Diane (wife)

For the two remaining participants conversations with their relative were not as readily recalled. In part patient preferences were assumed on the basis of established relationships affording in-depth understanding the patient. For Jane, decision-making around caring for her husband at home was based on trust and her early commitment to look after him:

I guess he just trusted me. Um because it was just a foregone conclusion that he knew that I would look after him. And um...yeah. And I think even the last time here at the hospice, he wanted to come home again... I loved him so much, and I made a commitment to him, or said to him a way back, years beforehand in his earlier disease process, that I wanted to support him till the end. So I suppose if we'd said it once, and that was it. That we didn't need to talk about it again. Jane (wife)

The final participant, whose mother had only just moved into the region shortly after diagnosis and surgery of an aggressive brain tumour, did not recall direct discussions with her mother regards place of care. Rather the conversations were had with the participant's husband and children:

I don't think we discussed exactly where she was going to die, but [Husband] and I had a conversation with the kids about whether they were comfortable if Mum died here, because this is their home. And they said that it wouldn't be right if she- it wouldn't be right for them (for Mum to die elsewhere), and she wouldn't like to go anywhere else. I don't think I actually had the conversation with her. We talked in depth about the funeral, and what she wanted um but I think it was just assumed that she was going to die here with us as long as I could manage. Fiona (daughter)

There was congruence between patients expressing a wish to be cared for at home and preference on the part of participants to enable this to happen. Endeavours by participants to solicit patient preferences by way of direct conversations predominated. However the data also revealed for some participants, a reliance on their understanding of patient preferences based on in-depth knowledge of their relative.

Beyond place of care, some participants spoke of conversations held with patients on matters relating to arrangements for funerals and/or burial. It would seem these matters were discussed and facilitated by participants, independent of the HPCS. Willingness of participants to disclose these often poignant and private accounts was unexpected and profound for me as a privileged listener.

For Geoff his absolute commitment to his wife extended to travelling out of town at her request, to identify her burial place. This was a significant act for him at a time when he found being apart from her most stressful:

I actually went down for er the last time when she was in the hospice and that was about three weeks before she died, she sent me down to [Place] and, her family doesn't know this either and my family never knew this but she sent me down to [Place] and to find to pick out a spot for her and she had an idea where she wanted to go...She was in hospice and I was talking to her on the (cell) phone and I said, "Where do you want to actually go on this bloody wall?" And she said, "If you go and stand in the church door and you look up the valley and just walk in a slight angle," she said, "and about three

metres from the left of the gate,” she said, “you’ll see two flat stones.” And I said, “I can see them.” And she said, “That’s where I want to go” and I said, “Righto darling, I’ll see you tonight.” And flicked the phone off. Geoff (husband)

A week later Geoff prompted further discussions upon observing his wife’s increasing tendency to sleep:

And that’s when I said to her, “I think you’d better discuss the colour of your coffin you want and the hymns you want and who you want to speak at it and who you don’t. And so we sat down in the room there all one weekend, just her and I, and I kept bringing her more coffee and she came to this kingfisher-daisy colour and and I’m so glad it got painted like that, it was beautiful when it was finally done and er she had the hymns and all the speakers that she wanted. Geoff (husband)

For Barry a significant turning point in his ability to talk about his death and wishes came following his request to see a priest and subsequent reconnection with the church from which he had become estranged years earlier. This was observed by his second wife Diane to be a significant watershed moment, opening the way for him to broach sensitive matters relating to his burial:

From that day on, Barry was at peace, and was able to talk about death, able to talk about what he wanted. And then one day, he was very much in pain. I had to put pillows on the seat of the car, so that it didn’t bump him too much. But we had to have a trip to [Place] cemetery, because he said he didn’t need...it was my decision. There was a double plot with his wife, but he didn’t have to go there, if...what it was what I wanted. So I thought about this, and I didn’t have a problem, him going with his first wife. But I said I did need to be mentioned on the headstone. I felt I didn’t want to be nobody. So we had this trip to (the cemetery), and we got...got him over to the headstone, and yes, he thought we could have the words on there. Got back to the car, and he just...he was just sitting there. So I just sat and we just sat quiet. And he said to me, “You could still come with me, if you’d consider cremation,” he said, “you can still come with me when your turn comes’. So we left it at that. And yes, he... from that moment on he could talk about...and he wasn’t scared of dying. Diane (wife)

Jane learned of her husband Richard's wishes for burial through a family member, as oppose to a direct conversation with him, which she did not find unexpected:

Although I guess I should have assumed [with laugh] quite a bit with my dear husband, because there was a lot of things we talked about, and the rest I had to just guess. There was one day, about a year before he died, when he told my brother, who was visiting, that he was going to be buried over there under the gum trees. Well that meant [Place] cemetery. So that was affirmation about he was okay about being buried and where. So we...no, that was about all we did talk about, sorry. Jane (wife)

Facilitating preferences for patients was a central endeavour to all participants as they supported care of their terminally ill relative. Extending beyond place of care, patient preferences encompassed a variety of wishes including arrangements for funerals and burials. Whether preferences were ascertained by way of direct conversation with the patient or supposed by participants on the basis of their intimate knowledge and understanding of the individual, participants were a key conduit through which such preferences were realised.

4.4 Sustaining the role

Increasing understanding of the enabling factors carers experienced as supporting them in their role and sustaining their contribution of care has been of key interest in this study. During the data analysis process, key themes emerged from participant descriptions of the various supports they engaged and experienced. At times comprising a diverse montage of formal and informal supports including health care providers, family, friends, workplace and social agencies, the nature and experience of various supports described by participants as sustaining them in their caring role could be broadly grouped into four key sub themes: enhancing carer skills and confidence, are we there yet?, working with carers and easing isolation.

The presentation of each sub theme individually and evidenced by excerpts from interview transcripts, is purely illustrative and not intended to suggest they are separate entities in their own right. Rather these sub themes were often interrelated with participant descriptions of supports engaged and experienced at times demonstrating elements of more than one sub theme.

4.4.1 Enhancing carer skills and confidence

When asked to reflect on their family caring role, all participants were able to nominate self-identified skills, strengths and life experience, which provided the foundation for further knowledge and skills to evolve as they assumed their supportive role:

Remaining fairly pragmatic and calm when things went belly up. Um know, I'm a thinker which I tended...I have a tendency not to panic at times, to be able to get on with it, and when you know, without majorly going to pieces, but to get on with it at the time. And I think that was partly also something that um I'd sort of exercised when I was in the police force. You couldn't, you had to get on with it and do it. Yep. Wheels still going round, yeah...so the practical skills... I think there was strength that came from knowing, and being reassured that what I was doing was the right thing. Mary (sister)

Existing personality traits worked to support skill acquisition by some participants:

What I found worked best-well, this is just me personally I mean I you know I'm a thinker. I like to know what's going to happen. I like information, I ask questions, I seek answers. That's just who I am. So what worked for me...I'd say (to the hospice nurses) "What's going to happen next?" And they would tell me what's going to happen next. Then they would-then I'd say, "Right what skills do I need to have to be able to manage in that stage?" So when she was unable to turn, how do I do that? Fiona (daughter)

For two participants, being registered nurses aided navigation of the health care system, to best meet the individual needs and circumstances of the patient. Knowing key people and having freer access to information was an advantage for them:

Because of my nursing knowledge and experience, and how the support works (community care agency) and that work, I contacted them and he was entitled to have some respite. Um and I used that, and instead of going somewhere, which I felt was inappropriate for him, we had a carer come into our home, so I could go away for about ten days and walk the Milford track. Jane (wife)

I knew the (health) system, and that certainly does help, when you know contacts, you know people, you know roughly how the system works. Kate (daughter)

Another participant nominated an inner strength and comfort that came to her through her religious beliefs and prayer:

Well I have a strong faith, and I just knew that I'd never be given any more than I could handle [tearfully]. Diane (wife)

Previous caring experiences were varied and provided a strong foundation that influenced caring practice for all participants:

I was quite comfortable with medical procedures. So I knew that wouldn't be a problem. I knew I could do that. Um like my son has a bee-sting allergy, so I've always got to be administering adrenalin if he gets a bee-sting. And for a while we had a syringe (driver) unit, so I was quite comfortable giving um...I could quite easily give subcut(aneous), or into the muscle, I was quite experienced at doing that. So doing, you know, things into a butterfly valve wasn't a problem for me. It didn't...things like that didn't freak me out. Fiona (daughter)

Acquiring knowledge specific to caring for a terminally ill relative came for most participants through support of health professionals:

When I realised she was coming home, I spent two weeks in A T and R. I'd go in there in the morning, at- I'd drop the kids to school, whip home, sort out what I needed, head in there about eleven and spend the rest of the day with the nurses to learn how to care for Mum, how to do all her personal cares, how to do all that sort of stuff, get used to her routine, to get an idea of what I was doing because I realised it was going to be quite intensive. So I got to know a lot of the staff in there, and [Speech Language Therapist] in particular was just awesome. She used to ring me up to see how I was managing once a week, say "How are you going? How are you managing? What do you need help with?" Because the big thing was the lack of communication, and she was really good at giving me tips for how to communicate (with Mum). Fiona (daughter)

Learning of and understanding the needs of someone who is unwell became broader focus overtime for most, and learnt 'on the job'. Accommodation of a change in pace offered the reward of new insights and some precious moments. The importance of slowing down and not being constrained by time was echoed:

It's understanding [slowly] understanding the needs of someone who is that unwell. Learning....so like they walk so much slower. And they need time to do a task. But they

still need to be able to do it for themselves. And having...having ...do you know what I am trying to say? It's understanding the whole process of being slowed down...so you need to give them time. And everything takes longer. The understanding you need to give the time to make the task happen so, they... so neither of you get frustrated. It doesn't actually matter if it takes twenty minutes to put on a top. It doesn't matter.
Fiona (daughter)

Now because time wasn't my enemy, we would- if Mum was ready to talk, we'd just sit and talk, and we'd just sit and talk about stuff. And she told me things I never knew about her. And I remember one time, we were just in absolute hysterics and I had tears running down my face. I was laughing so hard about something she told me...And it was just- I just got a new insight to her. Fiona (daughter)

And how long it takes, and how much...like I remember one day Dad wanted me to cut his fingernails. And you know, I was busting a gut to get somewhere that day. But I did sit down and do them. And he said, "Oh, it's the best thing that's happened to me all day". And it really puts it all in perspective. You think, "Oh cripes", you know. He just...it was...they were annoying him. And um yeah, you just have to remember that yeah, you've just got to slow down and be in the moment. Kate (daughter)

Alongside skill development, participants described their need for ongoing reassurance so as to validate and inspire confidence in what they were doing. Reassurance came from a variety of sources:

Well I'm sure the visits from the um nurses, when they were coming, always gave me confidence that everything was um... we were doing our best for him. And that kept me going in that area. Diane (wife)

I think probably that just the friends and the neighbours that were just constantly in contact, but I would say the family and the hospice were the two that enabled me to carry out what I saw was my...in a way, my responsibility. I guess when I say I'd always gone into bat for Joan, I guess I'd always felt responsible for her as well. And I was pretty upset that in the end, there was nothing I could do for her. You know? So that um that was relieved a bit by having other people reassuring me that I was doing, you

know, the best I could. As well as having them contribute. That I think was important.

Mary (sister)

Feeling reassured by visiting health professionals for one participant extended to her appreciation of an external check on her father's condition and support with decision-making:

And I think that's one of the things I felt, that I was making a lot of decisions, probably more than what I should have, in some ways, because you can't really be that objective when it's your own you know, your father. So it was good to have other people. And I think that's why it's good...even though phone contact is great, that's why it's great to have people (visit)...But that's really good because you get to see the patient with your own eyes, and if something's not quite right, you know, you can say, "Oh look, try this", or "Do...have you thought of doing this?", or whatever. And I think they're the things...because you know you're really introspected, and you're all tied up in it, you don't always see the other things. Kate (daughter)

4.4.2 Are we there yet?

Together with requiring ongoing reassurance in their caring role and in what they were doing, most participants also reflected a concurrent struggle of not knowing how long the patient had to live and how long they must sustain their role. This was acknowledged as difficult to predict, but affirmation of when the patient was entering the final stages of dying became important:

And towards the end I thought "Jeez, I can't do this for much longer. I can not keep going at this pace, at this intensity". Not knowing whether it was going to be the end tomorrow, or it was going to be the end in a week, or it was going to be the end in a month. And I mean, when you start out, I mean [Dr's name] thought she'd have six months minimum. I mean she only had three. So if you know you've got three months you'd ignore everything else, and just use those three and treasure every moment. But...you know, I roughly thought six. So I thought, okay, you've still...life's...six is quite a long time in the kid's lives. Life's still got to go on. Fiona (daughter)

I think that's probably about the time where I ...that I needed some emotional support was when I could see Barry really slipping, but nobody had given me any direction that it was happening. That I just yes, and I even look back now, and I hear people say, "Oh look, they've given so-and-so a few months", or "They've given so-and-so a few

weeks". I felt, not that I didn't want... I know nobody can actually say that, but I sort of at times didn't have a direction of how long is this going to be? Are we losing Barry, or is this a long... er yeah, I had a difficult time at that time, of just almost wishing somebody could just say, you know, you realise Barry is dying. But nobody actually had. Diane (wife)

For Jane, a phone conversation with her husband whilst she was out of town signalled a significant change in his outlook:

Because one of the staff actually rang me up while he was here at the hospice, because Richard wanted to speak to me. And when he spoke to me he said, "It's got closer". And I said to him, "Richard is that your... you know your death?" And he said "Yes". Well no, sorry, he said "It's got shorter". I beg your pardon, he said "It's got shorter". And I said, "Is that your life?" And he said "Yes". And that was ...what, about ten days before he died.

Despite their conversation, Jane recalls at the time she didn't fully register Richard was days from death:

Then he said they were thinking about catheterising him. And I said, "That's a great idea", because I thought, at least, you know, he won't be up and down in the night. Thinking that Richard's life journey had still got quite a long way to go, not recognising that he would be dead in ten days.

Having never witnessed a death before, a pamphlet about recognising dying given to Geoff by the HPCS early on in his wife's admission to the service, proved important for him and his family:

And when she did start to die, I just bought out that wee pamphlet, and I said to the kids, "This is what's going to happen, this is what's going to happen with Brenda when she's, in the last week." And it was down to a T exactly what happened....It really did (help). I could say to the kids, "Don't go away today, because she's going to die." I could see the change in her skin colour. She got pneumonia and her breathing was terrible. Geoff (husband)

For Mary however, her sisters pending death was to a degree unannounced and followed a cherished evening sharing ice cream. This time with her sister has since proved a comforting memory:

She was lying there, and I was talking to her in the evening, and she suddenly put her head up. And she was listening. And I said “Can you hear something Jane? She said “Yes”. And I listened and I listened, and away [emphasised] in the distance, I could hear Mr Whippy (ice cream van). And I said to her, “Do you want an ice cream?” she said “Oh yes”. So I got a bowl of ice cream, and fed that to her, she ate almost the whole bowl full and really enjoyed it. And then we talked for a while, and things. And then she just went off to sleep from that and she didn’t wake up. Mary (sister)

4.4.3 Working with carers

The number and composition of supports described and engaged by participants varied over time and in response to the changing needs of the patient and the participants supporting them. Some supports demonstrated a high degree of effectiveness and responsiveness to participant and patient need. Such experiences afforded participants ongoing confidence to engage such supports as this example demonstrates and enabled proactive symptom management:

And I guess that was really important to me, because it made me feel like I was doing something. I wasn’t just the person who was who was doing what they were told, I was making decisions about what I felt needed to change, and if something wasn’t working, I’d talk to the hospice nurse if she happened to be there, or I’d talk to... ring up [General Practitioner] and say, “Look I’m not happy with this. I think we need to change this”. And he’d go, “Yep, sure” and I like detail, and I like notes. So I was keeping notes and things like that. And [General Practitioner] would ring me up and say, “Right how many milligrams did she have yesterday?” and I’d be able to tell him exactly. And he’d say, “Yup, Okay, so we’re going to change this and this and this”. And it worked really really well. Because I felt like I was being proactive, rather than reactive.....It was very proactive, and it felt really good. Fiona (daughter)

Feeling acknowledged by health professionals and part of a team was a positive experience for all of participants, affording them the sense that people were working in unison with them:

So having a good GP, who worked well with the hospice nurses, and having a good pharmacy, all working together. It was there to help me. It wasn’t me trying to battle a

system. I mean I could have had some GP who didn't....who wouldn't listen to what I was saying, or wouldn't let me make decisions. Not that I made decisions, but yeah.
Fiona (daughter)

One thing I did like as well is, I was...I was appreciated by you girls, because I'd written [with chuckle] such a very detailed daily plan of what Richard's day normally was, and what he did. And I felt that helped his change from being at home to coming into the hospice. I felt that was really important...And because of medications. It was quite important he had them at the right times, and all that sort of thing. Because I've been a nurse for a while, and having had my nurse time, I just knew that a daily routine was really good for the next group of people to know about...I felt reassured he would be taken care of the way he was familiar with. Jane (wife)

Establishing good relationships with health professionals was by no means a passive exercise for family carers. Good rapport was clearly an active pursuit prioritised by one participant who resided rurally and had limited family and social supports when caring for her mother:

I had really good relationships with my health professionals. Because I made it work. But I am a communicator, that's what I do. Um if you know how to ask questions, then you can get the answers. Maybe people don't know how to ask questions. Maybe they don't know the questions to ask. Fiona (daughter)

Relationships with health professionals in some instances were well established, valued and acknowledged as key supports by participants:

Right at the end, his GP...Dad had been under this particular GP for many, many years, and knew him actually even before...Dad was involved in the firm that built his GP practice, and so had actually known him for a long time. And he came round, ...and after Dad had died, to do the death certificate and you know, all the paperwork and stuff. But he was great, because I knew Mum needed something, and he gave Mum some sedatives that would...just got her through the next few days. And that was so good. And just the way he came in and picked up Dad's hand, and...and I could just see him looking at Dad, and remembering the person that he was. Kate (daughter)

Some interactions with health care services were experienced on occasion by participants as being less than sympathetic to their needs and situation. Initial responses upon contact were

important and had a substantial impact on participants in terms of how supported and/or acknowledged they felt:

So we had this system that I would ring up the inpatient unit staff and say, "It's Fiona, my mother's name is Sandra, I'm about to give her so many milligrams of morphine, the time is such and such." "Oh no hang on stop stop stop, you can't do that. And I'd wait while they go away and check Mum's file...and they come back and say "Well how many milligrams are you giving?" And I'd tell them and "Who are you again?" You know that was frustrating, where the community nurses just said "go for it", because they knew my level of expertise and they were quite comfortable. Having to continually explain yourself to the inpatient team was frustrating ...They were really uncomfortable with me administering the drugs. But everything- Mum was never in pain, everything matched. I never lost any, I never took any [small laugh]. So that was- from my perspective, that was frustrating. It was different from what they were used to. They weren't comfortable with that. Fiona (daughter)

At times supports seemed geared less around the context and needs of the patient. For one participant a request to present her very unwell husband to a GP practice appointment was a distressing experience. Only a week before his death, a disconnect in communication between the HPCS and GP practice appeared causal to a lack of awareness by the practice of how unwell he had become:

Well okay, us being us felt we had to keep that (appointment). Well it was such a big job getting Barry dressed, let alone in the car to get to town. And we did it, we got there, and of course I mean, by this time, I had my arm right around his waist, and almost walking for him. And he collapsed on me in the middle of the car park. And an elderly couple, who I don't know to this day who they were, came to my help, and we managed to get him to the surgery... Barry sat in the chair, and he looked at doctor, and said, "They can't find out what's wrong with me, and I don't know myself." And [GPs name] was...we had to go there for him to tell us that it was the cancer that...you know, there was no more that we could do. And to me I felt, why did we have to do that? Probably, I suppose, medically-wise, if we'd had...if Barry had died, and I had to call the doctor, he needed to know where he was at. Because he actually hadn't seen Barry for all that time, when he was under (the hospice). I guess there was a reason for it. Diane (wife)

For one participant an encounter with hospice volunteers in her home shortly after the death of her mother indicated a lack sensitivity and understanding:

One thing I will comment on is the um the volunteers came to get the bed the day after Mum died. And she- I mean, she wasn't in the bed, obviously [laugh] and the body was gone, but I hadn't even had a chance to take the sheets off the bed, or anything. And I just wanted, I just needed to take the sheets off the bed. And they came in, and they started ripping the sheets off the bed. And I got really upset, and said, "Can you just give me five minutes?" No no no, we have to take the bed". And they pushed me, and they rushed me. And I needed to have five minutes to myself to take the sheets off the bed. Then it was a bed. But they needed to be more understanding of the fact that we'd been through this huge emotional upheaval and the beds in our lounge. They needed to be just a bit more respectful of that, that this person's died; it's not like dying in a hospital. Fiona (daughter)

In terms of managing concurrent employment during the time patients were on the HPCS programme, three participants resigned from or, in the case of one self-employed participant, deferred work commitments over this time to totally focus on supporting care of the patient. Three participants were able to retain their jobs, due to flexible working hours, leave arrangements and significant understanding expressed by both colleagues and employers of their situation:

I've got to say my work colleagues and I don't know if that's in there, but my work colleagues and my immediate boss was absolutely marvellous and I cannot speak highly enough of my work colleagues and my boss for the support I had for really since she got for the last seven years really. Um when any time I needed to be off to help Brenda or support her or take her to hospital, or to hospice, which was regular, or to scans I just went and my pay carried on and I can't ask for anymore than that. Geoff (husband)

Supporting a terminally ill relative at home requires a significant care contribution on the part of family carers that, if to be sustained over time, cannot occur in isolation from wider health and social support networks. For participants in this study, feeling acknowledged as part of a supportive health care team focused on meeting their needs and the needs of the patient had a significant impact on supports they engaged and their degree of confidence and reliance upon them. Furthermore, for those required to retain their employment beyond bereavement, access to flexible work arrangements, leave allowances and significant understanding by managers and colleagues enabled them to do so and sustain their commitment to care for their relative.

4.4.4 Easing isolation

For all participants, providing care for a terminally ill relative at home was a period that was increasingly restrictive both practically and socially and thus, to a degree, an isolating experience. As the patient's illness progressed, trips outside the home became less plausible. Easing the sense of isolation was an important theme revealed by participants and supports described that ameliorated this and maintained a level of connectedness were varied. The role of family and friends in maintaining contact and reducing the sense of isolation for both the family carer and the patient was prominent in participant accounts. Contact in the home in varying capacities was highly valued and included: meal provision; sitting and reminiscing with the patient; managing visitors and minding the phone to allow the family carer time to sleep; checking in on the patient whilst the family carer was at work; and taking dependent children on outings out of the home. Offering relief in terms of staying over night with the patient was mostly delegated to recognised family members who would take turns as able to support care in this manner:

Yeah. People brought some meals. And um actually the best support was really when some of Dad's friends would just come, and just sit there. And you know, I could just leave them to it. I just thought that that...I mean, I was you know, in the last sort of four days, um he didn't really know they were there. But it was just lovely to see people that you know, some really good old friends, um just come and sit there. And some just sat there and talked, requiring no response from Dad, you know for a couple of hours. And that was great, because you thought, you know, they're in good hands, there's...just let them have that time together, and um and you could leave. Kate (daughter)

And I have got some um very good friends. And there were times where I'd be really, really tired, and once again [Friends name] and her husband, they would just arrive. I can remember when... we couldn't get any food into him (Barry), and they would arrive with a picnic on wheels. Everything, I just had to sit down, not ...even to the serviettes. Everything came. And we'd sit out on the decking, and Barry and [Friends husband] would just reminisce. They'd just go off back to the 1950s. And we'd have this picnic, and then we'd clean up and [Friends name] and I would go for a walk, just down the road and come back again. Those things, arriving with bath salts for me to have the baths. Um just those escapes. Diane (wife)

Living in a rural situation with a limited social network the sense of isolation was at times palpable for one participant when her family were at work and school. Contact from visiting nurses was to become an important buffer:

So I would feel guilty if I would take up too much of their time. And I didn't want- and I suppose I had no-one else to talk to. That I might go a whole day, and the only people I'd see would be Mum, and the hospice nurse and my family. No-one else. No one would ring me. I didn't ring anybody because I was too busy. And you don't want to um feel you're taking up the hospice nurses time. I think the emotional stuff is more important than the physical. Physical you can deal with drugs, but the emotional stuff to keep the patient happy, and the carer feeling they've got someone to talk to, but then most people would have support. Fiona (daughter)

Formal carers coming into the home provided more than assigned personal cares to the patient. All but one participant had formal carers engaged in the home and described their presence and manner as providing regular connection with the outside world and respite on a number of levels for both patient and participant:

The hospice provided [carers name] to come in and help with washing her each morning. And that was particularly good, because it was a different person. She was cheerful. She'd come in a chat away to Joan, and it was a different face, and it was someone who wasn't...because I think Joan was also aware of the emotional impact it was having on me; because she got thinner, and of course her hair fell out, with the chemo and everything, there were times that I actually found it hard to look at her. And she realised that. And I was sort of making an effort, but it was really hard to look at what she had become. Mary (sister)

And she, Brenda, was a very strong moral person and um she was very very private and she didn't really want anyone else to wash her body or touch her body, you know, um so I did that for a while until she realised it was getting too much for me as well. And then we got this lovely lovely lady who came in to do it. She was very gentle and she wasn't like me...this lady was very modest and covered her up in the bed bath and she was absolutely wonderful yeah. Geoff (husband)

For some participants the formal carers visit enabled some time out of the house or opportunity to attend to other relationships:

She was there from 8 till 9.30, that's right and she would do the shower with Mum, and then I'd whip home and take I'd take the dogs for a walk or I'd go for a quick run, or something like that. So I had 8 till 9.30, um then [carers name] would come back for half an hour at night and just help get Mum into her pyjamas and do her teeth...So when she was here for that half hour at night, I would spend half an hour with the kids at night. I'd read a story, I'd sit and have a cuddle. I'd have half an hour that was just the kids and I. That was my time that was not negotiable. So I had them for half an hour at night. Fiona (daughter)

For Jane, whose husband had a long term chronic illness, there was immense gratitude towards the formal carer who had supported the care of her husband for the last 3 years of his life. Together with the flexibility of the home support agency, this support became pivotal in enabling her to maintain her paid employment and income whilst keeping her husband at home:

The caregiver who came to Richard, she didn't give me emotional support but she...the one sense, but then in another sense, the fact she kept coming, and she just thought Richard...she just adored Richard. And that gave me an emotional boost as well, because I kind of felt that I had somebody else on my side that could help him. Jane (wife)

As Richards's illness progressed and needs increased, flexibility of the home support agency was crucial:

So we just altered things. I was very, very appreciative of the home support agency, who were able to adjust to help me through that stage. Jane (wife)

Timely access to support when needed had considerable influence on participants' experiences and sense of isolation:

I do remember that we had a problem on a weekend day...And that was the one time I, you know, that I can clearly think of, where I felt I was a bit out of my depth, or I needed more support. Something had gone wrong with his medication, I think. Perhaps his syringe driver- I can't quite remember. But I paged her (community nurse) or phoned her on her cell phone. But in fact didn't hear back for a... I left a message,

didn't hear back for quite a few hours. Um and there were reasons for that. Um but that was kind of when I felt a bit kind of on my own, I guess. Kate (daughter)

4.5 Now and looking back

Final questioning in each interview invited participants to reflect of their caring experience and comment on what they consider important for health professionals to understand when supporting family carers in this endeavour. The opportunity for participants involved in this study to reflect on their caring experience gave rise for all to identify positive reward from supporting their relative's care towards end of life. Together with honest acknowledgement of the physical and emotional suffering encountered in the role, significant solace lay for participants in the knowledge they had succeeded in achieving the patient's final wishes which seemed to offer some counterbalance to their loss and comfort in their bereavement.

Establishing rapport with health professionals was enhanced if participants felt their role and knowledge in supporting care of their relative was recognised and respected. Participants consistently revealed throughout their interviews extensive and indepth knowledge of their relative's illness and care needs. In the case of Jane supporting a husband with long term chronic illness, she offered convincing justification for health professionals to listen to carer expertise:

And I think for um health professionals, even though they may have had education about some of these chronic illnesses, that the carer knows a hell of a lot more...because a lot of disease processes aren't textbook. You know, they're very individualised. And most probably for people with cancer as well. They could be very individualised. They are not a textbook situation. So um listen to the carer, I think is really, really important and acknowledging the carer of how much they've actually put into the situation. Jane (wife)

Especially towards end of life in-home contact and support from the HPCS and formal carers was increasingly important for all participants. Whilst phone contact was valued, it did not compensate for regular visits to the home as death approached:

...I think the important thing is just having frequent contact, I think because that kind of validates what you're doing, and it props you up to keep going. And um so even if the contact is quite brief, the regularity of it, the frequency of it I think it's quite important. Kate (daughter)

And I think that people have got, you know, like if you want to keep someone at home, and the most important thing is keeping them at home, when you get to that real end, when it's really intense, you need to have that extra help, so you can keep them there. Like I almost gave in. Fiona (daughter)

Overwhelmingly participants were positive about their experience supporting end of life care at home, identifying both personal satisfaction and comfort that supported them into bereavement:

It's not for everyone, but I think that people who want to do it probably do feel that they've been a...been able to contribute something significant, that's certainly how we felt. Kate (daughter)

I have no regrets, really, of um wishing we'd done this or done that, and that I was pleased I was able to fulfil his wish of dying at home. Diane (wife)

I think I knew that what...I mean, within myself, I knew that even though I was scared of what might happen, I knew I would deal with it. And I did. Mary (sister)

It's emotional, it's hard, physically, mentally, but it's so so rewarding. Geoff (husband)

Benefits for the wider family in terms of special time and greater access to the patient and valuable life experience for younger family members was also described and attributed to the act of supporting death at home:

One of my children in particular has said numerous times how thankful he is that I looked after him at home, so that he and his children could be there as much and see Grandad as much in that last stage as possible. So it was a very rewarding time, if people...you know if families are prepared to give it a go. Jane (wife)

All of us were really close...It was hard on every single person in the family. But the kids got to see that life and death is just natural, it just happens. I mean Mum died here in the lounge. Fiona (daughter)

Ongoing assessment of family carers coping especially for those with more limited social supports was deemed important by one participant:

I think you need to keep an eye out for people who are not going to ask for help, but possibly need it. You know what I mean? That they... they say their coping, and particularly if there is no-one else coming in, like I had family...And their having broken sleep and things like that. Mary (sister)

For two participants, expression of grief during the time of caring was done in private or suspended, and carried over into bereavement:

There was a pile of cigarette butts out there (in the garage) that you wouldn't believe. Um I would put her to bed, I would go out there and I'd cry for hours and hours and hours out there and then I'd come in and wipe the tears and have a drink of water and I'd go in and say with a big smile, "Hello, love. How are you? What would you like? (cheerily) And she'd say, "Well I need my pills now and I need this, can you get me a cup of coffee, or a cup of tea?" and I'd happily go away and get it. Geoff (husband)

Encountering clinical depression early into his bereavement, Geoff maintained grieving privately whilst caring for his wife was his way of coping, and he wouldn't have done it any differently:

Nothing was going to change Brenda dying, nothing was going to change me being apprehensive about it. Um I didn't show that in front of Brenda, I didn't show that in front of anybody else, I didn't show that in front (daughter's name) or my children. I didn't show that in front of my work colleagues. I was a blowhard. I'd say, "I'll be right, I'll have another woman in my bed in no time" you know, and all that stupid nonsense and that to give me the boost I needed, that was my nature. Everybody thinks I'm a big bloody rough man, but underneath I'm very, very, very soft, and I'm very emotional you know. Geoff (husband)

For a daughter open grief was 'on hold' and difficult for her to access whilst busy caring for her mother:

I think that um...sometimes you get so emotionally wrapped up in it that it's just so...you can't um...I think I bottled up the stress, and bottled up the tears, and bottled up the upset for so long, I forgot how to let them go. And I'm still dealing with that now. Fiona (daughter)

Most articulated new life perspectives following their caring experience and for some a powerful desire to offer support to others encountering a similar experience:

I know I'm different. I don't get wound up about things as much as I used to. A lot of things are a lot less important than they used to be. You know how you get sometimes a little carried away in the detail, and you go rush, rush, rush [whispered]. You know, life's too important you've got to live for the moment. Yeah it was a really special time.

Fiona (daughter)

4.6 Summary

This study aimed to explore and describe end of life care in the home from the perspective of family carers and excavate the nature of their care contribution and conditions under which they were able to sustain their role. The words of participants provided a powerful narrative of care giving in this context. This chapter has presented subsequent findings and the key themes pertaining to the nature and experience of various supports described by participants and their final reflections on their caring experience. The following chapter presents a discussion of the key findings as they relate to current literature, identifying implications for health care professionals and service providers supporting end of life care in the home.

Chapter 5. Discussion and Conclusions

5.1 Introduction

The participants provided rich descriptions of their caring role and supports they engaged and experienced when supporting the death of their terminally ill relative at home. Distillation of the findings and key themes outlined in the previous chapter are now presented as a discussion alongside current literature. The discussion has been grouped under the three key themes identified and will relate findings back to the original intent of this study: to explore and describe the key conditions under which family carers who supported end of life care in the home were able to sustain their contribution of care. Implications for health professionals and service providers supporting end of life care in the home is presented and study limitations outlined. Finally my reflections on becoming a researcher conclude the chapter.

5.2 Perception and acquisition of caring role

Whether participants in the present study acquired their role gradually over many years or suddenly over a few months, supporting care through to end of life served to both extend and deepen existing bonds held with the patient. This is aligned to findings of several studies, where family carers report heighten appreciation of and enrichment in existing relationships with their ill relative especially as death approached (Hyatt, 2006; Stajduhar, 2003; Waldrop et al., 2005; Wong et al., 2009). Irrespective of the familial relationship held with the patient, all participant accounts related compelling expressions of love for them. This underpinned their commitment to care and transcend, any physical and emotional hardship the role imposed on them. A strong relational base was described in terms of mutual love and reciprocity that was both given and received. This supports the premise identified elsewhere that care giving is essentially an interpersonal exchange from which caregivers can also draw strength and wellbeing from the care recipient (Braun, Mikulincer, Walsh, & Rodin, 2007; Wong et al., 2009).

Whilst participants all described positive relationships with their relative, contrary evidence exists to suggest that this may not always translate to wider populations. Gott et al. (2004) highlighted the supposition of positive family dynamics in which members are willing and

able to give and/or receive care from one another is evident in much palliative care policy but this is not always the reality. Mounting societal and health care system expectations for the delivery of palliative care at home, coupled with the family carers strong sense of obligation to the patient may for some carers exert undue pressure to assume the role (Munday, Dale, & Murray, 2007; Stajduhar, 2003; Visser et al., 2004).

Whilst these findings overwhelmingly found that participants willingly assumed their caring role as the patients illness progressed, previous research has shown this may not always be the case. Some relatives may inherit a caring role by default, as the only person available or in a time of crisis and once assumed they may find it difficult to renounce the responsibility (Payne, 2007). Stajduhar's (2003) ethnographic study convincingly highlighted the dynamic social context of home-based end of life care and the need for health care professionals to ensure there is consideration and ongoing review of family carer needs, wishes and abilities alongside preferences of the patient. Whilst preferences for place of care may be canvassed, flexibility and ongoing dialogue between the patient, family and health professionals is paramount, as multiple factors including the clinical course of the illness, limited resources, and inherent unpredictability of dying, may impose changes over time to the plan and/or place of care (Evans, Cutson, Steinhauser, & Tulsky, 2006; Tzuh Tang & McCorkle, 2003).

Gott et al. (2004) posed concerns that dying at home may be idealised, suggesting that, as death approaches, the reality of care and burden on family can in some instances prompt changes in patient preference. Plausible concerns they implied, arose around quality of care at home if the health of family carers is under threat or perhaps family values in relation to physical intimacy limit support in the case of children caring for a parent. Findings within this study did not provide strong evidence of such concerns which may be attributable to the relative youth of the participant group. Willingness to support physical care regardless of the familial bond held with the patient may be reflective of changing circumstances necessitating renegotiation of roles and relationships with adjustment of relationship norms, which has been recognised in previous research (McMurray, 2004). These points considered, it is clear that decision-making processes around preference for place of death are multiple and complex with any number of influencing factors changing as the patient's illness progresses (Tang & McCorkle, 2003).

Significant focus for participants in their caring role lay in determining or eliciting the preferences and wishes of patients. This was a natural pivot point for their endeavours to optimise patient choice and individualise care. A plausible premise within palliative literature is that a patient's verbal expression of a wish to die at home is preliminary to its realisation, by enabling family, friends, health and social services opportunity to plan for and mobilise the necessary supports (Brazil et al., 2005; Gomes & Higginson, 2006; Munday et al., 2007; Pemberton, Storey & Howard, 2003; Tzuh Tang & McCorkle, 2003). In my study, the majority of participants readily recalled direct conversations with their relative on the matter, which propelled their efforts to enable it. However for two participants patient preference for home death was not discussed but implied and this too holds some parallels with previous research.

Lowes (2010) phenomenological study of seven bereaved family carers revealed, in the main, patient preference for place of death was deduced on the basis of knowing the patient well as oppose to direct discussion. Lowes offers the supposition that an absence of direct discussion may be a protective mechanism on the part of patients towards their carers. This study found that unspoken decision making of this nature was perceived by participants to be almost instinctive and comfortably based on in depth understanding of the patient and established trust. Beyond place of care, arrangements for funerals burial became increasingly important for patients with participants revealing compelling examples where they went to great lengths to facilitate wishes in a variety of ways. What this study perhaps adds to current literature is that, regardless of a whether patient preferences are deduced by direct communication or implied, from the perspective of family carers, either means has potential to powerfully generate impetus to enable and achieve death at home for the patient.

Internationally, assertions that public opinion favours end of life care at home, over dying in hospital or care institutions are chiefly underpinned by assumptions that the home environment affords the patient a greater sense of control, dignity, comfort family presence and normality (Brazil, Howell, Bedard, Kruegar, & Heidebrecht, 2005; Tzuh Tang & McCorkle, 2003). This study strongly reflects these sentiments with participants preferring to care for their relative at home, where they deemed the patient's physical and emotional comfort and access to family and friends was least restricted.

Descriptions of maintaining vigil and close physical proximity to the patient towards the end of their life were consistent amongst participants. At a time when the patient's physical and emotional needs were often intensifying towards end of life, participants found devolving care giving responsibilities imposed its own stresses, only made bearable if trust and rapport was established with substitute supports. Similar research identifies reluctance of caregivers to be separated from the patient or to delegate care to another for prolonged periods, as key obstacles to uptake of carer interventions such as short term inpatient respite (Harding & Higginson, 2001).

Hyatt's (2006) comprehensive phenomenological study of bereaved spousal caregivers highlighted that reunion following physical separation towards end of life, or more importantly prevention of it, afforded caregivers' relief, along with a sense of accomplishment and comfort. This is consistent with evidence in my study where participants, regardless of their familial relationship with the patient, indicated separation or contemplation of it imposed anxieties for them especially towards end of life.

This perhaps has implications in terms of hospice inpatient respite. The premise of a temporary planned hospice admission providing a break for the carer is largely under researched, in terms of proven benefits on carer outcomes (Payne et al., 2004). Flexibility in how respite is offered and acknowledgment that one manifestation of it, namely inpatient respite, may not always be the most appropriate way for family carers to receive relief, needs to be considered (ibid). The planned respite programme policy of the HPCS within the study site implies that physical separation and/or relinquishment of caring tasks and responsibilities affords carers temporary reprieve of the same and a chance to replenish oneself. Whilst those who utilised this service were grateful for the support and care of the patient, it wasn't without concurrent struggle due to the separation it imposed.

Grinyer, Payne and Barbarachild's (2010) qualitative study evaluating respite provision by a children's hospice in Northern England from the perspective of service users offers some useful insights. Participants (parents) overwhelmingly acknowledged respite provision to be important in enabling them to maintain care of their child at home, allowing protected periods to focus on other siblings and 'normal family' time. However the study also identified some issues relating to power, choice and control over access to the respite programme, which parents felt unable to articulate previously for fear of appearing ungrateful recipients of the

service. Termed as “grateful passivity” (p. 508), the authors suggest a power differential can be unconsciously imposed by care providers that has potential to disempower families and “renders the service users grateful recipients of charity rather than active players and partners” (p. 510). Whilst the study population differs from those of the present study, relevance exists as to the importance of engaging and involving the intended recipients of support in the development of services, to ensure assumptions around family carer needs correlate with those identified by carers themselves.

Exploration and evaluation of how an array of respite options may allow more tailored support is advocated (Payne, 2004). Comparison of respite options that allow the family carer to stay alongside the patient in an inpatient setting or indeed provision of in-home respite services for those carers, who find physical separation from the patient or temporary relinquishment of caring duties carries its own undesirable burden, may be beneficial. Currently under researched, empirical knowledge of the efficacy of respite services from the perspective of carers and patients, would be valuable in determining congruence with service provider assumptions and resource allocation (Payne et al., 2004).

Predominant altruism of family carers is a strong theme within palliative care literature and often presented as problematic for health care professionals endeavouring to assess and address the support needs of family carers (Morris & Thomas, 2002; Soothill et al., 2001). Descriptions of how the dying patients expressed wishes and autonomy are often given precedence over the needs of family carers from the perspective of family caregivers was convincingly captured by Carlander, Sahlberg-Blom, Hellström and Ternstedt (2010). Their qualitative descriptive study identified how often family carers perceived their supportive role as core to the care of their increasingly dependent family member, giving rise to a strong tendency to yield to the needs of the patient before their own. This altruistic tendency was clearly demonstrated within my study but also carried a self-sustaining quality in terms of galvanising participants’ compulsion and/or commitment to support care of the patient to the end. Whilst being altruistic is not without struggle, how health professionals can best to support this tendency without undermining its seemingly sustaining qualities warrants exploration. Future research on the positive aspects of altruism and its role in supporting end of life care is advocated to enhance understanding of its place in sustaining both the commitment and coping of family carers.

5.3 Sustaining the role

Over time participants in the present study were providing a myriad of physical care tasks and emotional support to patients. Their commitment was underpinned by their prevailing love for the patient and doing what was necessary to support their care at home. Descriptions of episodic trepidation and uncertainty induced by changeable and at times unpredictable symptoms and patient needs, had potential to challenge their capacity to cope and induce anxiety. Significant counterbalance to such anxiety lay in having ready access to reliable supports and information that enhanced their carer skills and confidence, worked with them and eased their sense of isolation as the patient's illness progressed.

Milberg and Strang's (2004) longitudinal study of carer coping reached similar conclusions, identifying key factors that enhanced both the comprehensibility (perception that the challenge is understood) and manageability (perception that resources to cope are available) of family carers supporting palliative care at home. Important factors enhancing positive psychological states of family carers despite their burdening situation included: open and accessible information; prior knowledge of illness and dying; empowerment; support (informational, practical and emotional); and competence (in self and health professionals). Unpredictable situations, they conclude, were deemed more manageable where family carers experienced a sense of 'togetherness' with the patient and health professionals and felt supported in decision-making.

Stepped acquisition of knowledge and skills by participants in anticipation of evolving patient care needs was evident within the findings. Predominantly participants sought tutorage from formal carers and health professionals entering the home or, as for one participant, from ward staff prior to her mother's discharge from hospital. The importance of knowledge to family carers is prominent within palliative literature in terms of reducing anxiety, aiding decision-making and enhancing their sense of control and authority (Convey, Ede, & Sealey, 2008; Morris & Thomas, 2002; Wilkes, White, & O'Riordan, 2000). Alongside this potential barriers to learning are acknowledged, such as physical strain and impaired attention that can curb family carers' ability to "receive, filter and act on supportive information" (Hudson et al., 2004, p. 23). The imperative by many health professionals to give information must therefore not exceed consideration of its relevance and timeliness to family carers, if not to overwhelm them (Bee, Barnes, & Luker, 2009; Grande et al., 2004; Morris & Thomas, 2002).

Understanding the family carer's perspective of the patient's illness and the information they desire as the illness progresses, requires established rapport and ongoing assessment by health professionals to ensure information is timely and tailored to their needs (Waldrop et al, 2005).

Whilst carer skills and knowledge evolved over time, all participants were able to identify varying existing skills, strengths and life experience that they could draw on to support new knowledge acquisition. Acknowledgement and endorsement of existing skill sets and the contributions participants had made to patient care from health professionals was a predominant experience and highly valued by participants. This result was consistent with evidence from Hunstad and Svindseth's (2011) qualitative study which explored the experiences of bereaved spousal caregivers. Factors they deemed influential to their willingness, confidence and ability to support care at home included feeling acknowledged and affirmed in their role by health professionals and having ready access to competent, holistic support and advice out of hours.

Ability to assess patient symptoms, anticipate evolving care needs and navigate appropriate help from health care services were deemed crucial by participants and achieved through a variety of informational supports. Participant descriptions of empowerment were linked with timely and co-ordinated information and support from health professionals, enabling proactive symptom control. Wilkes et al.'s (2000) cross sectional qualitative study offered a similarly persuasive account of the varying informational needs of rural families caring for palliative oncology patients. Explored perspectives of families and specialist palliative care nurses highlighted the importance of information to families in enabling effective care of the patient and that informational needs varied throughout their palliative care journey.

As the patient's illness progressed so too their care needs intensified as end of life approached. For most participants this time was accompanied by internal struggle as they endeavoured to balance their continued capacity and capability to fulfil their supportive role for an unknown duration of time. Concern predominated for many that personal limits, in relation to their coping, may be reached before their relative's death. Seeking confirmation from health professionals of when death was approaching for the patient and how to recognise this became an increasing focus for most participants, alongside realisation this phase would signal time with the patient was drawing to a close.

Stajduhar's (2003) ethnographic study illuminated the social context of home palliation where biomedical influences in the home provided both positive and negative experiences for family carers. Necessary and welcomed by many family carers, hospitalisation of the home environment (equipment & supplies) could also be imposing. This is comparable with the results of this study where predominantly participants associated loan of hospital equipment as enabling care at home and optimising patient comfort.

An unexpected finding however was that for two participants, hospital beds installed in their respective homes proved to hold significant symbolism for them. Upon delivery of a hospital bed, an argument ensued between one participant and his ill wife, as for her its arrival was confronting and signalled to her the beginning of the end of her life. For another participant following her mother's death, when volunteers arrived at her home and proceeded to dismantle the hospital bed despite her pleas to allow her time to remove the bedding, strong emotions were aroused. Until the bed was void of linen, for her it was a significant symbol of the experience she had just shared with her mother, and it caused her great upset to not be granted time alone to perform this final act. These accounts highlight that, sensitivity to the symbolism some supports may come to hold for patients and family carers should not be underestimated and mindful negotiation should guide installation and extraction of such supports.

Conflicting communications with health professionals were encountered by some participants that at times served to challenge their role and level of competence. A hospice inpatient triage nurse's disapproving tone and lack of familiarity with the plan of care, when a participant phoned in to report she had administered pain relief to her mother, was affronting and frustrating for her. This contrasted with the encouragement she received from the community palliative care nurses who provided training and endorsed her competence to administer subcutaneous medication. Previous research has highlighted the importance of communication and how interactions with health professionals can have a significant impact on family carers encountering terminal illness and feelings of empowerment to provide care (Duhamel & Dupuis, 2003). Such findings highlight the fact that first responses matter and for family carers, every encounter with health professionals can bestow a powerful impression in terms of what support they can reliably expect from a given source.

Relationships participants established with service providers and health care professionals within this study were, in the main, positive. Where support services strove to understand and yield to accommodating individual need, participants described strong appreciation of supports being flexible, available 24 hours and working with them. Hunstad and Svindseth (2011) reflect similar findings in their examination of the views of bereaved spousal caregiver's on determinants of quality home care at end of life. Flexible and responsive care tailored to family needs and based on holism were important factors ensuring carer satisfaction, especially as care needs changed frequently during the terminal phase. Access to effective communication and information has been linked closely to enhanced carer confidence in and uptake of supports (Aoun et al, 2005). Communities where formal health care services and resources are limited, comprehensive support to family caregivers may not be feasible creating tension between palliative care philosophy and reality (Hudson et al, 2004).

Wider supports acknowledged outside the home included the availability of flexible work arrangements and supportive colleagues, enabling half of the participants' continuation of their employment and income whilst they supported care giving at home. This finding supports recommendations elsewhere in the literature, that if family carers are to increasingly replace formal carers in this context, it is imperative that government policies enable employers to allow such flexibility and the retention of income alongside caring responsibilities (Aoun et al., 2005).

Mobilisation of kin and social support networks by participants for the most part occurred without HPCS input. This is evidential of the broad social needs that accompany dying at home and the significant role social and community networks can play in meeting them. Leadbeater and Garber (2010) suggest the specialisation of palliative care has to some degree disenfranchised the role and place of families and communities in care of the dying:

It is only comparatively recently that dying has become institutionalised and professionalized in the developed world. For most of history people coped with death through social and religious rituals at home and in communities (p.69).

The role of families in caring for their loved ones forms a key part of a discussion paper on the language and discourse that has evolved with the specialisation of palliative medicine (O'Connor et al., 2010.) They suggest wider recognition by health professionals of the role of

families in caring for their loved ones is essential to re-establishing it as a familial and communal task. Clear examples exist within this study of family and community resource engaged by participants and subsequent contribution to enabling care at home.

Formal carers in the home were engaged by most participants and acknowledged as providing more than assigned physical care of the patient. Important social and emotional needs of the patient and indirectly participants were also addressed. A paucity of knowledge within the palliative literature on the role and contribution of formal carers in this context is evident together with variation in terminology assigned the position and ambiguity of its scope (Devlin & McIlfatrick, 2009).

Devlin and McIlfatrick's (2010) mixed method study was conducted in two phases and offers some useful insights. A postal questionnaire (n=69), ascertained how home care workers perceived their interest, training, support and supervision in providing palliative and end of life care in the home. Approximately two thirds had not received any training in palliative or end of life care, with over half identifying it as an additional learning need. The majority rated palliative and end of life care as a key and rewarding component of their work, that involved talking and listening to clients and families alongside providing personal care. Notable variation in their role and associated tasks was evident with a number carrying out additional duties not indicated in their task sheet, relating to home management. Perhaps not surprisingly, insufficient time allocations for duties and travel times were identified as problematic, imposing unrealistic time constraints for most.

The study's second phase comprised a focus group and purposive sample of community palliative care link nurses (n=6) to garner their perspective on the role and contribution of home care workers in this context. A predominant view revealed was of home care workers being primarily providers of physical care, with limited acknowledgment of the emotional impact of caring on home care workers. Participant perspectives within my study, add weight to the value and contribution of formal carers in this context and the frequently broad scope the role attracts. Contact with the outside world, brief opportunities for participants to leave the home to visit friends or spend uninterrupted time with children, were recognised and valued social and emotional supports that participants attributed to the presence and flexibility of formal carers.

Ingleton, Chatwin, Seymour and Payne (2011) usefully offer a broad evaluation of a pilot service model in the UK that encompassed carefully selected and specifically trained formal carers, supervised by district nurses to deliver palliative care at home. This service model aimed to address policy directives to improve end of life care and facilitate greater numbers of people to die at home. Stakeholder interviews with district nurses, service managers, administrators and bereaved family carers who experienced the service concluded: health and social care provided by the formal carers was positively appraised by family and patients as contributing to achieving quality care at home and preventing unplanned hospital admissions; more collegial as opposed to subordinate relationships existed between formal carers and district nurses; and implementing the service model achieved improved retention of formal carers in the service. The impact of such initiatives in complementing and enhancing the expertise and resources of family carers appears promising and worthy of further research.

Acceptance of formal carers in the home often came after a period of adjustment whereby participants credited the communication skills and manner of formal carers entering the home as enabling them to embrace their support. Similar findings by Gott et al. (2004), highlighted the importance family carers place on health professionals and formal carers developing positive relationships, contributing to their feeling care is not being delivered by strangers in their home, a place often synonymous with “friends and family” (p. 465). Hudson et al. (2004) identified the multiplicity of health care providers supporting care and entering the home at this time, has potential to overwhelm family carers and hinder development of trusting relationships. This was not a strong finding in my study, which may be attributed to the small sample size or the care-coordination role assumed by the HPCS, as part of contractual requirements conferred by commissioners of the hospice palliative care service. Stajduhar (2003) concurs that experiences can be improved by reducing the number of health care professionals entering the home, through improved communication and care co-ordination between various health care services, enabling regular protected private family time.

Echoed by participants in my study was the importance placed on developing positive relationships with health professionals and formal carers that in turn enabled them to at times, entrust and devolve their caring responsibilities. Uptake of support from formal carers was also influenced by participants being able to identify positive gains and respite for patients in terms of the physical care and social interaction.

5.4 Now and looking back

The plea for health professionals to acknowledge and listen to carer expertise and the importance this held for participants throughout their time caring for the patient was well articulated. Whilst often supporting care over a number of years, participant's accrued significant levels of knowledge in relation to the patient's illness, care needs and medical management. Endorsement of their knowledge and contribution to the patients care by health professionals, contributed significantly to participants feeling empowered and supported. How consumers encounter health professionals and the health care system has been described previously in the palliative literature and can powerfully determine their level of access and engagement of services and support:

We must recognise how the processes of engagement and interaction need to empower before effective care can be delivered. Listening to users' narratives can help us to challenge our own perceptions. (Oliviere & Monroe, 2004, p.4)

These factors would suggest that if family carers are to be engaged in supporting end of life care in the home, health professionals need to examine and challenge possible assumptions of the primacy of professional knowledge over experiential knowledge of carers.

Frequent in-home contact from the HPCS was a significant support valued by participants especially as the patient's death approached. As care needs of the patient intensified so too did the participant's need for frequent validation of what they were doing. In terms of feeling confident and able to support care in the home through until the patient's death, these interactions were deemed pivotal by participants. The value of face-to-face interactions also lies in the ability of health professionals to more ably tailor information (written or verbal) to specific concerns and/or context of the carers (Payne, 2004).

Personal transformation following their caring experience, for most participants, occurred by way of a life review of what held importance for them and a new desire to support others encountering similar experiences. This result was consistent with evidence from previous studies where the majority of family carers have described life enriching opportunities arising from time spent with the patient, enabling new insights to unfold of themselves and the patient (Stajduhar, 2003). Joy and suffering were acknowledged by participants and threaded

throughout their accounts. Wright's (2005) seminal text acknowledges and discusses the linkages between spirituality and suffering as derived from listening to illness stories or narratives of patients and family experiencing serious illness. She concludes that "suffering is life wrenching and life altering, yet it can be life giving" (p. 30), and so presents the dichotomy that serious and/or terminal illness can impart on those who encounter it.

Previous research exploring the positive aspects of caring, as subjectively constructed by bereaved informal carers, similarly identified key themes including, discovering personal strength, relationships developed or enriched with the care recipient and personal growth (Wong et al., 2009). Whilst it is not stipulated in this work where patients died nor how long post bereavement participants were interviewed, parallels between these findings and those of my study are plausible as in both, participants are able to reflect on their "experiences as a collective whole" (p.187). For example in my study most participants portrayed how learning to understand and accommodate the needs of the patient imposed a change in pace and perspective, creating a new consciousness in which time did not constrain or predetermine their priorities. 'Being' became more important than 'doing' and when participants yielded, the experiences shared with patients provided precious and treasured memories. Carlander et al. (2011) noted similar findings amongst families caring for a member close to death at home with their accounts revealing change in their appraisal of time. An uncertain future cast renewed commitment to treasure the time remaining and "striving to live to the full in the present without postponing it" (ibid, p. 692).

Reflection on their end of life caring experience gave rise for some participants to identify the impact it had on their ability to grieve whilst supporting care and into their bereavement. One participant treated for clinical depression a year prior to her husband's death, identified his diagnosis of myelofibrosis as the key trigger to an intense grief reaction. For another participant grieving in private whilst caring for his wife was his way of coping at the time. He was adamant not to disclose his grief to anyone and firm in his belief, that the loss his wife's death would bring was inevitable and could not be eased by anyone. For a daughter living rurally with limited social support at her disposal, a sudden introduction to four months of intensive nursing care of her mother rendered her grief 'on hold' and difficult for her to access until after her mother died.

These accounts reflect the variability in grief responses. Lee's (2009), descriptive study of registered nurses caring for a dying family member at home similarly identified their tendency to suspend their emotions whilst coping with the demands of care giving. By compartmentalising their emotions they felt better able to maintain clarity in their thinking to aid decision making. Also by maintaining their composure they felt better able to offer emotional support other family members. Some also went on to experience acute mental and emotional turmoil followed the patient's death. Strong conclusions are not offered here other than this is a significant area for further research, so as to identify how best to support grieving by family carers in this context and minimise adverse bereavement outcomes.

5.5 Implications for practice and service provision

For health professionals and wider support services that contribute to end of care in the home, evidence from this study highlights a number of factors that family carers positively appraised as enabling and sustaining their caring contribution. Positive relationships with both the patient and health care professionals; flexible and tailored supports in the home; acknowledgement of carer expertise and an "equal powerbase between clinicians and non-clinicians" (O'Connor et al., 2010, p. 70), conferred a strong commitment to the task and sense of empowerment.

Evidence presented here suggests significant resource can exist at individual, family and community levels and may manifest in a number of ways. Time invested by HSPC services and health care providers listening to family carers' and 'mapping' these existing skills and supports can contribute to accurate appraisal and understanding of what supplementary support and resource is required to enable and sustain family carers'.

"Necessity is the mother of invention" (author unknown), so too when circumstances dictate ordinary people, it would seem, can accomplish extraordinary things. Points for reflection by HPCS and health care providers could include how deficit or needs based models of care that currently predominate health care policy, have potential to obscure our vision of the resource, resilience and skills' existing within families and communities and perhaps how our role may be to recognise and embellish such resources. "Resilience-orientated services foster family empowerment as they bring forth shared hope, develop new and renewed competencies and strengthen family bonds." (Walsh, 2003, p. 16)

We can meet peoples aspirations to die at home only if people are provided with proper support (Leadbetter & Garber, 2010). Viewing family carers supporting end of life care in the home through the lens of resiliency theory has potential to prevent over medicalisation of their needs and foster acknowledgment of the emotional and practical supports that can and do exist within family and community networks (Walsh, 2003).

5.6 Study limitations and future research

Alongside presenting this study's findings and associated discussion it is important to acknowledge limitations and view findings with these in mind. Of note this was a small study with participants recruited from only one HPCS provider within one geographical region of New Zealand. Attempts were made to provide sufficient description and detail as to the setting and context to enable readers to ascertain congruence with their own practice context and experience (Polit & Beck, 2006). Purposive sampling techniques also endeavoured to obtain maximum heterogeneity in participant characteristics, in the hope of allowing wider applicability to varying familial and social contexts.

Also acknowledged, is that these participants were relatively youthful with little revealed in the way of significant health issues of their own, other than two participants who experienced clinical depression. In both cases support and help was successfully obtained independent of the HPCS, through friends, family and primary health services. It has been noted that older family carers face the potential for health issues that significantly alter their ability to realistically support home palliation, especially in relation to physical care tasks (McMurray, 2004). Such impediments can impose further disadvantage if it renders older carers unable to access emotional and practical support to meet their specific needs (ibid). If as changing population demographics project, family carers are to be an increasingly older cohort, researching the experiences and needs of this group needs to be a research priority.

Exploration of financial strain incurred by participants whilst supporting care of patients was not highlighted in this study. Whilst three participants did maintain their employment via various means, the data revealed predominantly social reasons as oppose to financial implications guiding this. It is not suggested that financial necessity didn't underpin participant decision making in this matter, but more that my line of enquiry did not reveal this.

Within this study a deviant case can be identified in the participant who supported her husband with chronic illness for 22 years (Morse, 1994). Literature on long term carer burden has not been addressed in any depth within this study. Alongside other participants she shared the experience of supporting end of life care at home, however it is acknowledged and speculated that her experience in supporting her husband over a prolonged illness trajectory may or may not have further coloured her end of life caring experience. This, the experience of long term care giving in chronic illness, may well prove to be a valid entry point for future research.

This participant group comprised essentially a Eurocentric sample and lacked ethnic diversity. Findings therefore do not illuminate the potential influence of cultural and/or ethnic factors in supporting end of life care at home and/or access to supports. Future research that captures ethnic or cultural (e.g., gender) group differences could hold significant relevance to ensuring support services are sensitive and accessible to family carers from varying ethnic and cultural backgrounds.

Finally this study only captures a single family carer perspective and perhaps perpetuates the predominant representations within the literature of single primary caregivers as opposed to the shared care dynamics that more likely exist within varied family structures (Lingler, Sherwood, Crighton, Song, & Happ, 2008). Utilisation of mixed method studies that invite perspectives of wider family members would allow for triangulation of data and an enhanced image of the social context of family caring and end of life care in the home.

5.7 Reflections on becoming a researcher

As indicated within the methodology chapter, conducting this study has been a significant personal and professional journey for me into the realm of nursing research. Broader appreciation has developed of research processes that are not as linear as I first thought. The importance of reflexivity as a researcher was highlighted many times, none more so when for one interview, prepared photos on a kitchen table were to be viewed upon my arrival. This was an important starting point for the participant which I honoured, and preceded the interview. He wanted me to understand the person his wife was and the life they shared prior to her illness. Images from their courtship and early married life sat alongside a photo of her in bed a short time before she died. He showed me the bedroom in which his wife was cared

for in her final weeks. Understanding the ‘whole’ was important and extended beyond the interview schedule.

Evolution of my own nursing practice has occurred as I immersed myself in participant accounts and sought clarification of their perspectives, at times finding my own professional assumptions challenged. Renewed and deepened understanding has evolved of the rudimentary importance of listening to and respecting the stories of those we profess to support, and how establishing ‘connectedness’ with them precedes all else.

5.8 Conclusions

Supporting home based care of another person approaching the end of their life presents complex and unique challenges for family carers who assume the role. Family carers in this context are bestowed considerable responsibility to support the patient’s physical and emotional needs, and as death approaches, manage concurrent emotional needs of self and others. Alongside acknowledgment that family carers are pivotal to achieving home palliation, understanding what inspires and sustains their commitment to care over time is essential.

When participants’ felt their knowledge and role was recognised by health care professionals’ rapport and trust was fostered, cultivating engagement and access to various supports. Feelings of empowerment also stemmed from recognition of the significant contribution participants’ had made often over many years to the patients care. Assumptions that professional knowledge holds primacy over the experiential knowledge of family carers supporting someone with terminal illness are challenged in this study’s findings where significant carer expertise was evident and acquired over time.

Conflicting communications with health care professionals or service providers at times challenged the confidence and agency of participants. This study highlights that first responses matter, and that in them strong impressions can be conveyed to family carers. Confidence in and reliability upon varying sources of support or information is often established through early encounters. Moving forward, if dying at home is to be enabled, family carers must be assured of responsive, flexible and reliable supports and information from health care professionals and service providers.

Although unique to the New Zealand context, the findings within this study resonate with international research in the field, adding to the body of knowledge on family caregiving and end of life care in the home. Compelling participant accounts revealed that supporting the physical and emotional care of a dying relative, is a role both complex and diverse in nature. Whilst the role can impose on those assuming it an element of struggle or burden, study findings also revealed greater understanding of the natural resilience and strength family carers can bring to their situation and caring role. How health care professionals recognise such resilience, or perhaps even assume it in the face of carer stoicism or ambivalence is worthy of further exploration.

Finally this research also highlights the significant role and place of communities in supporting palliative care in the home, where kin and social networks and supportive workplaces can meet numerous non medical needs. The degree to which such informal resources (individual or community) are recognised and cultivated as vital contributors to home palliation and support for family carers is a legitimate topic that has not been addressed here and begs future research.

As these conclusions indicate this study has not culminated in any definable end point of understanding or knowing. Whilst study findings have enhanced knowledge of family carers and their experience of end of life care in the home, so too it has illuminated potential paths to onward journey in research and learning. That is as it should be.

Appendix 1: Participant cover letter

28 October 2010

End of life care in the home: Supporting and sustaining informal carers

Dear

Your name and contact details have been forwarded to me by the Family Support Service (), as someone who may be potentially interested in participating in the above research study. I have enclosed an information sheet and consent form for you to read and consider.

In about a week's time, I will contact you by phone to offer you an opportunity to discuss and clarify any questions you may have about the study. Following this contact, you may wish to deliberate for a further 2-3 days before you make your final decision to participate or not.

Yours sincerely,

Jacqui Bowden-Tucker, RN.
Principal Investigator.

Appendix 2: Participant information sheet

End of life care in the home: Supporting and sustaining informal carers. INFORMATION SHEET

Introduction

You are invited to take part in the above research study. Before you take part it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish. Ask us if there is anything that is not clear or you would like more information.

Thank you for reading this.

Why have I been invited to participate?

In this study informal carers are identified as the main person who provided unpaid practical and emotional support to the patient on a regular basis and was in contact with the palliative care team. The study will require 6 voluntary participants who have supported end of life care in the home setting, to share and describe their experiences of informal care and what factors enabled and sustained them in their caring role. The Family Support Service at Hospice Manukau has been asked to identify and offer informal carers who meet each of the following criteria, the opportunity to participate in this study. Participants are to be aged 18 years or over, at least four months post bereavement, well enough physically and mentally to participate, and able to give informed written consent to participate.

What is the purpose of this study?

This study is designed to explore and present the perspective and experiences of bereaved informal carers who have supported a terminally ill spouse, partner, family member or friend to die at home. There are no right or wrong answers to the study questions that will be presented and they will broadly cover the following areas:

- 1) The nature and frequency of care and support you provided for your spouse/partner/ family member or friend during the period of their illness and end of life care at home.
- 2) The key conditions under which you felt enabled to sustain your contribution of care and support end of life care at home.
- 3) Your description of the formal and informal support networks you engaged during the period of care.
- 4) Your perceived strengths or skills utilized during the time of caring and/or evolving over the time of caring, that enabled you to continue your supportive role.
- 5) How you perceived your own needs (emotional & physical) during the period of care and whether you were able to express and have these needs met or not.

It is anticipated this research will improve understanding amongst health care professionals of the experiences of informal carers supporting a person dying at home. It is also intended this information will help inform the development of targeted carer support and interventions that are both accessible and acceptable to carers and designed to minimize carer stress.

Do I have to take part?

Your participation is entirely voluntary. You do not have to take part in this study and your choice to participate or not will in no way affect the support you currently receive from the Family Support Service. You are free to withdraw from the study at anytime, without having to give a reason and this will in no way affect your future/continuing support from [REDACTED].

What will happen during the study?

You will be contacted by phone in a week's time by the researcher Jacqui Bowden-Tucker, to confirm if you wish to participate in this study. At this time you may wish to discuss the aims of the study and/or talk through this information sheet and clarify any questions or queries you may have. At this point the researcher will also discuss informed consent. You may then wish to consider these discussions for a further 2-3 days to reach your final decision. If you agree to participate, a date and time will be negotiated with you to participate in one interview of about 1 to 1½ hours duration, in a location most convenient and comfortable to you. The researcher can come to your home if you wish.

What are the possible benefits of taking part?

The potential benefits of taking part in this study include:

- 1) The opportunity to contribute your knowledge and experience towards positive improvements in support for informal carers in the future can be a rewarding experience.
- 2) The opportunity to contribute to new knowledge and improve understanding amongst health professionals of the experience of informal carers, caring for a person dying at home and how best to support this vital role.
- 3) Obtaining increased knowledge and personal insights about yourself and your experience as an informal carer through dialogue with researchers.

What are the possible risks of taking part?

The potential risks to your participation in this study are expected to be minimal but it is important for you to be aware of them and what measures are being taken to reduce them.

- 1) Emotional upset may occur if in the interview you recount an unpleasant event. To minimize this risk you are able to have a support person present if you wish. You may also ask for the interview to be stopped at any point if you are feeling uncomfortable or upset and you need some time to recover. Contact details are also available on request for grief and loss support.
- 2) Exposure of your identity is a risk with small sample sizes as in this study. Specific confidentiality protocols that included secure storage of research data are required by the researcher. These will be adhered to in this research and are designed to protect the identity and privacy of any research participant. This research has also been approved through the Victoria University of Wellington and regional ethics committees who have deemed the rights and privacy of study participants are protected.
- 3) Failure to recount accurately the information you provide. It is for this reason you are asked to consent to your interview being audiotaped so as information can be later transcribed to ensure accurate recording of your responses. Also the interviewer will take some brief notes following the interview to acknowledge points of key significance you present.
- 4) Impact on your personal time required to take part in interview. You are only required to attend one interview and it is intended to negotiate this to occur at a date, time and location most convenient to you.

Will my taking part in this study be kept confidential?

Yes. No material which could personally identify you will be used in any reports or presentations on this study. Throughout the research project collected data will be stored securely as required by the terms of ethics approval of this study, in order to maintain confidentiality and protect your privacy. Audio-taped interviews will be transcribed with your name replaced by a false name. The typist and researcher are bound by confidentiality agreements. On completion of the study any personal information including audio tapes will be destroyed as required by terms of ethics approval of the study. If you wish you may request the audio-tape of your interview is returned to you on completion of the study.

What will happen to the results of this research study?

The research findings will form part of a Masters thesis and will be further disseminated by publication in nursing journals and through conference presentations to health professionals. This study will take one year to complete and so there will be a delay between when information is collected from study participants and publication of the results. In any published or presented results data will in no way link or refer to the identity of any participant.

If you have any concerns or questions regarding this study now or in the future please contact the principal investigator below.

Principal Investigator:

Jacqui Bowden-Tucker RN

Masters student

Ph: 03 578 9492

Email: jacqui_bowden-tucker@nzf.salvationarmy.org

Research Supervisor:

Dr Jan Weststrate

Senior Research Fellow

Graduate School of Nursing and Midwifery

Victoria University of Wellington

Wellington

Ph: 04 463 5034

Fax:

Freephone:

Email: Jan.Weststrate@vuw.ac.nz

Complaints procedure

Should you have any concerns or complaints arise as part of this study in relation to the services you received during illness, these should be discussed in the first instance with the relevant health services manager. If you are not satisfied with this process you may wish to contact the Nationwide Health and Disability Advocacy Service toll free on 0800 555 050.

Appendix 3: Participant consent form

End of life care in the home: Supporting and sustaining informal carers.

CONSENT FORM

Request for Interpreter

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Maori	E haihai ana ahau ki tetahi kaiwhaka Maori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island Maori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fai manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
Samoan	Ou te mana'o ia i ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletalia ki na gagana o na motu o te Pahefika.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

Consent to participate in Research

I have read and I understand the information sheet for participants taking part in the above study. I have had the opportunity to discuss this study, and I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that I will be asked to talk about my experiences caring for and supporting _____ during their terminal illness and end of life care at home.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at anytime, and this will in no way affect my future support from the [REDACTED] Family Support Service.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports or presentations on this study.

I understand that to keep my participation in this study confidential I will be given a pseudonym. I know that any information that enables me to be identified will be removed.

I consent to my interview being audio-taped.

I agree to my interview being transcribed and understand that the transcriber has signed a confidentiality agreement.

I agree to provide information to the researcher on the understanding that it is confidential and that all my information/data will be kept secure. I understand that I can request the audiotapes of the interviews be returned to me at the end of the project.

I understand I will be informed when the study is available to be read.

I know whom to contact if I have any concerns regarding this study and am aware that the study has ethical approval.

I give permission to use direct quotes from my interview and am aware these may be used not only in this study but also in related articles and presentations.

I know I have access to grief and loss support should I require this service.

I _____ (full name) hereby consent to take part in this study.

Signature: _____ Date: _____

Researcher: Jacqui Bowden-Tucker

Signature: _____ Date: _____

Appendix 4: Interview schedule

Questions	Prompts for the interviewer
1. Demographics	
To begin with I would like to ask you some brief questions about yourself and the person to whom you provided care so as to give me an idea of your own particular situation.	
1.1 Carer's age, sex, ethnicity, marital status, relationship to the person that died? geographic proximity to patient? 1.2 Patient diagnosis/illness? When diagnosed? Length of time from point of referral to hospice palliative care services until death at home? Length of time since bereavement? 1.3 From the point of 's referral to hospice palliative care services and until his/her death at home can you describe for me how you saw your role supporting his/her care? 1.4 At any point in 's illness did he/she have any conversations with you in relation to his/her preferences for end of life care?	Did you live-in with during the time you were supporting 's care or were you living away from their home? How did this role change or evolve for you towards the end of 's life. If so, how did this impact you, in supporting their care at home? If not, how did this impact on you in supporting their care at home?
2. Caring activities	
I would like to ask you some questions about your role in supporting 's care from the point of referral to hospice services through until their death at home.	
2.1 Can you describe to me the variety of ways in which you supported care for at home? 2.2 During this period, did you see your role supporting 's care change, and if so how? 2.3 What other concurrent roles or responsibilities were you also carrying during this time?	How did you manage or balance these roles and responsibilities during this time? What were the greatest challenges for you in sustaining your caring role at this time?
3. Informational supports (written & verbal)	
I would like to now ask you some questions around the types and level of informational, practical and emotional support you experienced from the point of 's referral to hospice services until the time he/she died at home.	
3.1 In terms of <i>informational supports (written or verbal)</i> can you describe for me those you experienced during this period of care?	In what form was this information provided? Which information was most helpful for you during this time? From where/whom did this information come? How accessible and timely was this information for you?
4. Practical supports & instruction	
I would like to ask you some questions about practical supports/instruction you experienced during this time	
4.1 Can you describe what <i>practical supports or instruction</i> experienced during this period of care?	In what form was this practical support provided? What practical information was most helpful for you during this time? From where/whom did this information come? How accessible and timely was this information for you?

5. Emotional supports	
I would like to ask you some questions about emotional supports you experienced during this time.	
5.1 Can you describe for me the <i>emotional supports</i> you experienced during this time?	<p>In what form was this emotional support provided?</p> <p>From where/whom did this support come?</p> <p>Which emotional support(s) did you find most helpful during this time?</p> <p>How accessible and timely was this information for you?</p>
6. Wider informal support networks engaged	
I would now like to ask you some questions about the <i>wider informal/unpaid support networks (groups or people)</i> you engaged during this period of’s care.	
5.1 Can you describe for me the informal support networks, be they people or groups that you experienced during this period of’s care?	<p>Which of these types of support did you find most helpful for you in your caring role?</p> <p>In what way was that support most important for you?</p>
7. Self-identified skills & strengths	
I would now like to ask you some questions about skills and strengths you either possessed or developed during this period of care that you felt supported and enabled you to sustain your caring role.	
<p>6.1 Can you describe skills or strengths either existing at the time you cared for.....or that you developed during the period of care?</p> <p>6.2 What skills or strengths do you see as most important for informal carers to possess or acquire if supporting end of life care in the home?</p>	<p>What role do you believe these skills/strengths played in enabling you to sustain your supportive/caring role?</p>
8. Carers perceived needs (physical & emotional) during period of care	
Reflecting back on this period of care, I would now like to ask you some questions about what you perceived <i>your own physical and emotional needs</i> to be during this period of care.	
7.1 Can you describe for me what you perceived your own physical and emotional needs were during this time of caring?	<p>As you recognised these needs, were you able to express these to anyone?</p> <p>If so, to whom did you express these needs and how were they met?</p> <p>If you did not recognise these needs at the time, can you describe for me the key reasons for this?</p> <p>What other barriers existed for you, in expressing and/or having these needs met?</p> <p>What do you feel could have helped resolve these barriers for you?</p>
9. Impact of caring experience on life at present time	
I would like to ask you some final questions on the impact of this caring experience on your life at the present time.	
<p>8.1 Reflecting on your time supporting care of.....at home, are there any thoughts or comments you would like to make about your caring experience?</p> <p>8.2 Is there anything else you would like to say that you feel would be useful for health professionals supporting informal carers to know, about the reality of end of life care in the home?</p>	<p>What impact has this experience had on your life at this present time?</p>

Appendix 5: Transcriber confidentiality agreement

Transcriber confidentiality agreement

**To ensure confidentiality for the participants whose interviews I will be privy
to, I of**

state that I will not divulge any information in the transcripts I produce for the
researcher Jacqui Bowden-Tucker.

Signature

Date

Thank you for this agreement.

Signature.....

Date

Jacqui Bowden-Tucker

Researcher.

Appendix 6: Ethical approval letter

5 October 2010

Ms Jacqui Bowden-Tucker
Nurse Educator

Regional Ethics Committee
Ministry of Health
4th Floor, 250 Oxford St
PO Box 9307
Christchurch
Phone (03) 372 9337
Fax (03) 372 1015
Email upperouth_ethics.committee@mh.govt.nz

Dear Jacqui Bowden-Tucker

End of life care in the home: supporting and sustaining informal carers
Investigators: J Bowden-Tucker, Dr J Weststrate (Supervisor)
Ethics ref: URA/10/EXP/055

The above study has been given ethical approval by the Chairperson and Deputy Chairperson of the **Upper South Regional Ethics Committee**.

Approved Documents

Information sheet and consent form version 1 dated 1 October 2010
Interview schedule version 1 dated 1 October 2010

Final Report

The study is approved until **30 August 2011**. A final report is required at the end of the study and a report form to assist with this is available at <http://www.newhealth.govt.nz/ethicscommittees>. If the study will not be completed as advised, please forward a report form and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised if the study does not commence, or is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.
It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. The organisation may specify their own processes regarding notification or approval.

We wish you all the best with your study.

Yours sincerely

Alleke Dierckx
Administrator
Upper South Regional Ethics Committee
Alleke_dierckx@rnh.govt.nz

Appendix 7: Ethical approval letter

Regional Ethics Committee
Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3072
Christchurch
Phone 03 375 3007
Fax 03 375 3015
Email opasson@ethicscommittees.govt.nz

27 October 2010

Ms Jacqui Bowden-Tucker
Nurse Educator

Dear Jacqui Bowden-Tucker

End of life care in the home: supporting and sustaining informal carers
Investigators: J Bowden-Tucker, Dr J Weststrate (Supervisor)
Ethics ref: URA/10/EXP/055

Amendments

- Cover letter, version 1 dated 22 October 2010
- Interview schedule version 2 dated 26 October 2010

Thank you for submitting the above documents. These have been considered by the Chairperson of the [redacted] Regional Ethics Committee, and approved under delegated authority.

Yours sincerely

Alleke Dierckx
Administrator
[redacted] Regional Ethics Committee
Alleke_dierckx@moh.govt.nz

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