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**From Caregiving to Bereavement:
Weaving the Strands of Identity**

A thesis presented in partial fulfillment of the requirements

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“From caregiving to bereavement: Weaving the strands of identity”

Abstract

“In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?”

The identity of family caregivers in palliative care has been ambiguous: caregivers are often unaware they fit the description of ‘carer’. Previous research describes two contrasting constructs that shape the identity of the caregiver: burden and privilege. Research, including this study, suggests that the emergence of identity as a carer impacts on the course and experience of bereavement. Two semi – structured interviews were conducted with a small number of caregiving family members: during the caregiving role and in their subsequent bereavement. This exploratory study used phenomenological research to examine the experiences of those caregivers interviewed. The data were examined using the existential themes uncovered in analysis. This paper reports on those themes.

Acknowledgments

A book, thesis, or piece of writing is not merely a compilation of thoughts, but the reflective narrative of a certain period in a life. And because no single life is ever lived in entire isolation, every author is dependent on others for their support and input. It gives me much pleasure to acknowledge those others who have assisted me:

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CHAPTER ONE

INTRODUCTION

The heart has its own comfort for grief

**Janet Frame
Rain on the Roof. 1967**

Background and Outline of the Study

Introduction to concept

This research examines the experiences of family members who care for someone with a terminal illness. The study was designed to contribute to a deeper understanding of caregiving within a terminal illness and palliative care context. In undertaking this topic, I wished to explore the links with caregiving and the experience of grief in bereavement, the transition a family member makes from the role of caregiver to the new role of bereaved person. This transition, I posit, is parallel to the individual's sense of identity and is profoundly challenged by bereavement. The significance of death and bereavement are not easily minimised; they remain a philosophical, existential and spiritual matter that all people inevitably face, a boundary beyond which one cannot go. " ... the one who knows they are going to die is different from the one not confronted with imminent death" (Baird and Rosenbaum, 2003 p 11 on Jean Paul Sartre's protagonist in his short story "The Wall"). ¹

This study aims to explore, describe and present the narratives of those with the experience of being a caregiver and the experience of their grief in bereavement. The primary aim is to hear the voices of caregivers. Through narrative, experiences are validated and made sense of during the process of the telling. A good story is also emblematic of a larger story (Burke, 2008). In this way the experiences related in this research project, whilst belonging to the individual, may also be universal, in that death, dying and loss are elements of the human condition. The study addresses

¹ Perhaps the discussion on death and dying is more clearly articulated in and informed by the works of poetry and literature than in the medical and allied health palliative care articles cited in this thesis. There is no aspect of the human condition that has not been captured in poetry, song or literature. In recognition of this, each chapter title page of this thesis has a poetry or lyric quote. "Poems are the words we turn to when words fail us: when we're confronted with huge and conflicting emotions, when lives begin and end" (Johnston, 2008:21).

fundamental issues using a qualitative research approach which allows for the salient issues to be explored. For the purpose of this study, I interviewed family caregivers to elicit descriptions of perceptions and feelings regarding their own experience of the caregiving role. A second interview with those same caregivers took place around two months after the terminally ill person's death, where the emphasis remained caregiving, but focussed on reflections upon that role. I undertook this research whilst working as a clinical palliative care senior social worker in a hospice multi disciplinary team. The two threads of this thesis are reflected in my work as a palliative care social worker: support for the family during the illness and bereavement support.

Working with terminal illness can evoke powerful feelings of vulnerability, influencing both professional, personal and for me, academic, lives. To 'stare at the sun' is a term used when facing one's own mortality, (see for example Yalom, 2008). It has been suggested that it is impossible to truly imagine one's own death, because in the very act of imagining, we are, in fact still present as spectators (Freud as reviewed in Burt, 2002). We cannot imagine because in the unconscious we are each convinced of our own immortality (ibid). The act of preparing for another's death is the daily experience of caregiving at the end of life. "That confronting death allows us, not to open some noise-some Pandora's Box, but to re-centre life in a richer, more compassionate manner" (Yalom, 2008: 9). The notion of 'dual passports' is one employed by Susan Sontag: one passport to the world of the sick and one passport to the world of the healthy (in Altschuler, 2005). This metaphor accurately describes those family members who care for a terminally ill person.

Background

For social workers, in particular, loss and bereavement are prominent themes in our understanding of relationship breakdown and the loss of

social roles (Eva, Percy and Chowns, 2007). Therefore, an understanding of loss is integral for social workers working with people who have health problems or are encountering disability. Social work in a palliative care setting responds to the issues which arise for people during times of change in their lives. The goal of social work in palliative care is to help the patient and family deal with the personal and social problems of illness, disability and impending death (Doyle, Hanks, Churney and Calman 1998). This resonates with the International Federation of Social Workers' definition of Social Work:

The social work profession promotes social change, problem solving in human relationships, and the empowerment and liberation of people to enhance wellbeing. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work. (The International Federation of Social Workers, 2000 definition, *Social Work Review*, 2000: 2)

Social work addresses the barriers, inequities and injustices that exist in society, and arises in response to the problems and complexities of everyday living. Social work assists people in making sense of their world and their experiences. In the context of palliative care, defining the role of the social worker within a multi disciplinary team requires focus on social work assessment skills. Our expertise rests in gaining a thorough and sensitive understanding of people as individuals, family/whānau members, members of communities and the larger society. When clients tell their stories to social workers the application of both theory and practice allows us to unpack the way structural, economic and other factors have affected their lives (Frances, 2000). We then link private troubles to public issues: what affects an individual is frequently significant to a wider group. These values underpin my role as a palliative care social worker and have shaped

my interest in the place of family caregivers for terminally ill people. Enabling family members to play their role in caring for a dying person, and thereby strengthening the family in the long term is one of the defining contributions of social work to palliative and end-of-life care (Reith and Payne, 2009). The commentary and definition illustrate my role as social worker. It is now helpful to turn the discussion to what constitutes palliative care, hospice, terminal illness and end of life care.

Definition of terms

Palliative care is a mode of treatment where the primary intention is not to cure the disease but to enhance the quality and meaning of the life and death (Mehta and Ezer, 2003). Specialist palliative care integrates the physical, psychological, social and spiritual aspects of care for a terminally ill person, as well as support of the family during illness, dying and after the patient's death (Chapman and Bass, 2003). The origins of palliative care were synonymous with the hospice movement. As Becker notes in his 2008 editorial, the term palliative care was universally understood by the 1980s and 1990s as referring to the care of a dying person and their family in whatever environment, from diagnosis through to bereavement. The term is seen as non-political, non-religious and spanning across all cultures. As suggested by Clark and Seymour, palliative care must acknowledge the wider historic and social context in which it sits and "... has to be seen as an aspect of culture through which the dilemmas of human mortality are being dealt with at a specific time" (1999:179).

The World Health Organization definition and commentary is:

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 in Harding 2005:150)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organisation website definition).

In the New Zealand context, the New Zealand Palliative Care Strategy borrows much from the WHO definition, and attempts to advance guidelines for palliative care provision as well as to address funding issues.

It defines palliative care as:

...the total care of people who are dying from active progressive diseases or other conditions when curative or disease-modifying

treatment has come to an end. Palliative care services are generally provided by a multi-disciplinary team that works with the person who is dying and their family/ whānau. Palliative care:

- affirms life and regards dying as a normal processes
- aims neither to hasten nor to postpone death
- aims to provide relief from distressing symptoms
- integrates physical (tinana), social (whānau) emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family / whānau attain an acceptable quality of life
- offers to help the family /whānau/carers during the person's illness and their bereavement (Ministry of Health, 2001:2).

Hospice as a term is used in two ways (New Zealand Palliative Care Strategy, 2001). It can refer to the philosophy and practice of hospice care, which is in effect the same philosophy and principles of palliative care in previous definitions. It can also refer to a hospice unit. Usually this is a free standing unit with inpatient facilities, where palliative care is practiced, and which emphasizes medical and psycho-social care. Some hospices do not offer inpatient services (see appendix 7 of New Zealand Palliative Care Strategy, 2001).

Terminal illness refers to an active and progressive disease for which curative treatment is neither possible nor appropriate and from which death is certain. The period of time varies from a few days to a few months (ibid: 55).

Historical overview of Hospice

Hospice care dates back to the 12th century where the term (literally meaning a place of refuge or shelter) was attributed to accommodation run by the religious for travellers, often crusaders or pilgrims. These "*hospes*" provided care and hospitality to a cross section of the population

rather than solely to the dying, although the primary intervention was based on spiritual succour (Clark and Seymour, 1999; McNaught, 2002; Saunders, 1981). Early middle ages and medieval times were shaped by the powerful place of the church that mandated preparation for death was spiritual, not medical. By the late 18th century, the Age of Reason regarded death as orchestrated more by doctors than by priests, implying that death was a physical rather than spiritual process, transforming death from a natural part of the life cycle into a medical event (Aries, 1974; Kaplan, 2006; Redding, 2003). As death moved into institutions, families lost touch with the dying and how to care for them. The place of firstly the priest, then the doctor as orchestrator of illness and death is accepted academic lore. However, it is worth noting that the tradition of women involved in end-of-life and after-death care is stronger than the profession of men as priests and funeral directors. Women's role in caring for terminally ill family members signals a return to home as the place of death (Hera, 1995). Caregiving in an earlier era was less of an option and more of an understood personal and family responsibility (Kovacs, Bellin and Fauri, 2006).

The earliest foundation of the modern hospice movement is thought to be in Ireland, in the latter half of the 19th century, a nursing led movement from the Irish Sisters of Charity, a group of Catholic nuns (Ahmedzai, 1996; Clark and Seymour, 1999). A number of similar institutions established in Europe and The United Kingdom, the proto-type of current hospice, were all in a similar tradition: charitable, religious, philanthropic, moral and medical (Clark and Seymour, 1999). These attributes therefore located Hospices as charitable agencies within both the health and social care sector, and it was from these roots that the modern hospice movement had its origins.

By the mid 20th century hospitals in Western countries represented the face of medical advancement. The death of patients represented failure,

over which there was no ability to exert rational control (Burt, 2002; Walter, 1999). The 'medicalisation of death' refers to the culture in which death is seen as a medical failure, relegated to the back rooms of hospitals and somehow shameful, "death became the repugnant enemy" (Kaplan, 2006: xii). The 1960s saw a change in social order, with awareness of civil rights, women's rights, rights of ethnic minority groups and the 'rights' of the dying. This movement was fuelled by a back-lash against the prevailing bio-medical model of care. It was into this social context that the modern hospice movement was born. Cecily Saunders (later Dame Cecily) has been acknowledged as the pioneer of the modern hospice movement initially in the United Kingdom, then internationally. Her concern about the care of dying people made lasting impacts on service provision, medical care and the care of the bereaved.

Death and Dying

Death is no longer the last taboo, (reference to Gorer, 1965). Pictures or stories of other people's deaths are regular news items. Increasingly death is the subject of television documentaries, dramas and reality programmes examining most details relating to death (Beresford, Adshead and Croft 2007; Walter, 1999). Despite this, the contemporary view of death is not perceived as prevalent, as everyday, as in previous eras. The impact of disease, illness and accident is mitigated by the advances in technology and medicine. MacLeod (2002) suggests that death defiance in the 20th century stems from a belief that through modern science we are almost immortal, or as Hera puts it "hint at a promise of immortality for the future" (1995: 44). Medical science has changed the impact that disease and disaster have on mortality. This results in the Western world both being more familiar with death (at a distance) and further removed from death (in experience).

The culture of death changed dramatically during the twentieth century. When people died primarily at home, family, community and clergy assumed responsibility. As the location of death shifted to the hospital, physicians became the gatekeepers. As a result, death is now viewed through the lens of biomedical explanation and is primarily defined as a physiologic event. Most medical education and training reinforce this framework. However, a strictly biomedical perspective is incomplete. For most persons involved with care at the end of life, death is infused with broader meaning and is considered a natural part of life, not a failure of technology.... It may be useful to recognize that for most patients and families who are confronting death and dying, psychosocial and spiritual issues are as important as physiologic ones. (Steinhauser, Clipp, McNeilly, Christakis, McIntyre and Tulsky, 2003: 198)

Interest in the topic

For the purpose of this study the focus is on those who have cared for a terminally ill family member. This choice of this topic is informed by three major factors. The first is my own experience as a social worker working with terminally ill people and their families. I have been deeply affected by stories that clients have shared with me and the degree of resilience they demonstrate in harrowing circumstances. The second factor influencing my choice to study in this area is the jurisdiction that social workers have when working with family members and the bereaved. Working as an allied health member in a multi disciplinary team, the dominant discourse is often bio-medical. Bereavement support and close support of family members is the un-negotiated work of the psycho-social team members. The third reason is the demographics of life limiting illnesses. With an aging population, there is an expected increase in the prevalence of those who will be cared for by a family member. Because of these demographics,

the role of those carers is on the political agenda in the Western health and social care system. In combining both the experience of caregiving and the experience of bereavement, I have the opportunity to reflect on the dual threads of my role as a palliative care social worker.

My interest in this subject arose out of my work with families and the perceived gap regarding knowledge of the assistance provided to families who care for a terminally ill family member. When I began the study toward this thesis the role of the family caregiver appeared to be under-researched, under recognized. At the genesis of this project there also appeared to be a gap in related research addressing the issues of bereaved caregivers. The object of this research is to help fill that gap in the research of palliative care family caregivers and to provide a rich description of how these caregivers make sense of, or forge their identity as caregiver. I acknowledge that any meaning participants may make from this experience is uniquely their own, and is influenced by a cultural, spiritual and personal frame of reference. Given this understanding and the small number of participants, caution is advised in generalizing from this study. Qualitative researchers do not attempt to form generalizations that will hold in all times and in all places (Franklin and Ballan, 2001). On the other hand, findings may also be universal, in that death, dying and loss are elements of the human condition.

Overview/ Chapter Summary

This chapter has positioned the research within the context of specialist palliative care social work and provided definitions adopted for the purpose of this study. This research sits not only in the political/policy forum of care at home resulting from health reforms. It is also informed by, and developed from, an increased recognition of the rights and the unique position of carers. I have outlined the link between the role of the specialist palliative care social worker as the suitable person to undertake this research on family caregiving. When clients tell their stories to social

workers the application of both theory and practice allows us to unpack the way that family, structural and illness discourses have affected their lives. We then link private troubles to public issues as evidenced by the political and personal role social workers maintain. "Since social work began, practitioners have been actively involved in campaigning for others and seeking recognition of their needs" (Schofield, 1999:20).

This summary now turns to describe the architecture of this thesis, outlining the structure and how this thesis is presented. The voice of service users, as caregivers are, is increasing in importance to, and impact on, health services. Carers and caregiving literature are the focus of chapter two.

Chapter three outlines key loss and grief theories and the way these both influence and have been influenced by academic and therapeutic paradigms. This chapter details the experiences of grief and critically examines bereavement risk assessment tools.

Chapter four is divided into two sections. Section A presents an overview of the methodology employed in this study. Using a theoretical approach based on phenomenology my methodology maps the territory which informs this research. I am also guided by social work theory. Section B within this same chapter describes the method used to collect the stories of experience, outlines ethical issues and looks at both strengths and weaknesses of the chosen method. The interview participants are introduced.

The themes of the interviews are presented then analyzed in chapter five where I interpret the narratives of caregivers. The themes derive from the existential themes congruent with phenomenological methodology as articulated by van Manen, (1990). The first interview where caregiving is explored was vital to build rapport between the individual and myself. This

enabled a greater degree of sensitivity when approaching the second interview, a conversation about bereavement. The chapter ends with discussion on and conclusions about the caregiving themes and bereavement themes.

In the final chapter, I review the research process; discuss the limitations of the study, the clinical implications and recommendations for future study. Any recommendations are informed by the participants' narratives and the literature that echoes their experience. This discussion is examined in the wider context of the ethical issue of researching those who receive a palliative care service. The conclusion addresses the connection between caregiving and bereavement. This final chapter also allows opportunity for my own reflection on being a researcher. I explore a link between the role of the novice researcher and the role of the caregiver. The paper ends with a concluding statement.

I undertake this research whilst employed as a senior palliative care social worker within a hospice service in the capital city of Aotearoa/New Zealand. I have 25 years social work experience, primarily in the health and disability sector, thirteen of those in palliative care. I am New Zealand born of European/ Pākeha descent. I have been conversationally fluent in Te Reo Māori (the Māori language) for some 35 years, and have a sensitive understanding of Tikang (custom) and Māori world view. I am a daughter, sister, wife and mother.

"The gifts of grief"

The complete transcripts are not included in this publication. The interviews undertaken were poignant to read and to 'bear witness to'. Phenomenology recognizes the recordings of a particular event at a particular time. To witness the words of these women at this juncture of their life was truly a privilege. To pay respect to their stories, each participant has been given a bound copy of their two interviews. This

includes the participant whose first interview formed part of this research, but whose second interview took place too late for inclusion. As a palliative care social worker, I am aware that the months leading to a family member's death and those confused months following are seminal moments in time. Hence, for those women to retain a copy of their interviews concerning those months, was a way for me to honour their courage. Each transcript has a copy of a painting by New Zealand artist Rita Angus, "Tree" 1943 of which she wrote "... it is as though my life is in two. I am beginning the second half with a little wisdom and a little genius. I am free to flower if only for a few years..." (Angus 2008). The painting is of a solitary winter tree in a stark wintry landscape. The tree is represented in its' barren state. Looking closely there are subtle indications that the tree is about to break into bud - the promise of spring. This image reminds me of the gifts of grief. It was painted following the artist's own experience of profound grief. It is this same painting, in a post-card rendition that I have on my study wall above my desk, a visual reminder of the barrenness and beauty of grief.

CHAPTER TWO

CAREGIVING

The geological layers of our lives rest so tightly one on top of the other that we always come up against earlier events in later ones, not as a matter that has been fully formed and pushed aside, but absolutely present and alive. I understand this. Nevertheless, I sometimes find it hard to bear.

**Bernard Schlink,
The Reader 1997:215-216**

Caregiving

Introduction to concept

Support for the family is a key component of palliative care practice and philosophy. Most care received by cancer or terminally ill patients is provided in the community, in homes, by informal or unpaid caregivers (Bachner, 2007; Doherty, Owens, Asadi-Lari, Petechey, Williams and Carter, 2008; Exley and Allen, 2007; Harding, 2005; Milne and Quinn, 2009). Whilst the provision of palliative care is a specialist area, in fact much of the day to day care is provided by untrained, un(der)paid informal or family caregivers at home, who are propelled into this unfamiliar role. Families choose to provide care for many reasons, including enduring love, duty, affection, family responsibility and obligation, cultural expectation, lack of alternatives, or preference for avoiding institutional care. The effect on caregivers involved in end of life care has received only recent attention in hospice and caregiver research literature and practice (Allen, Haley, Roff, Schmid and Bergman, 2006; Payne, 1999; Payne, 2007; Rose, 2001; Salmon, Kwak, Acquaviva, Brandt and Egan, 2005). As well as reviewing the caregiving literature and the more sparse literature on caregiving in a terminal illness context, this chapter will provide a definition of terms and give an overview of caregiving for those with palliative care needs. As a phenomenological approach guides the study, I use the existential life world themes congruent with phenomenology as articulated in van Manen (1990). For a more extensive discussion see p 77 of this thesis. These themes are the corporeality, relationality; temporality and spatiality. This chapter details the evolution of the role, distinguishing between caring for and caring about. The next section demonstrates the political and economic influences on home care philosophy. I examine hospice philosophy and the impact of treatment advances. This sits against a backdrop of changes in family and societal structure. The concept of 'emotional labour' is explored in relation to caregiving work, the predilection of intimate relationships and the meaning of 'home'. Following

the definition of terms, then caregiving in the New Zealand research context, I conclude with a review of literature focused on caregiving at the end of life.

The Emergence of Caregiving

Families chose to provide care for their loved ones for many reasons. Family members may be propelled by moral, cultural, social or financial obligations to undertake the role of caregiving, sometimes without a clear understanding or discussion about the implications of that role. Caregiving is a role that may evolve over a period of time where reliance on a caregiver incrementally increases as a terminally ill person loses independence. The involvement of the caregiver increases as illness progresses, often reaching a point in which the caregiving role becomes an all encompassing job as the patient nears the end of life. For some, there may be no distinguishable point where the family or spousal relationship changes to 'patient' and 'caregiver', but rather evolves with no discernable starting point and caregiving suddenly becomes part of family life (Pierce, 2006). In the report prepared for Carers Victoria, Australia, Cole and Gucciardo-Masci (2003) note that many caregivers perceived their role as a 'duty', the denial of which would see them incapacitated by guilt. Values and beliefs held by individuals and families are significant factors which underpin the decision about who should be providing the care (Cole and Gucciardo-Masci, 2003), where the work of caring for someone is predicated on the existence of emotionally intimate social relationships (Exley and Allen, 2007). The logical converse of this is that some relatives may make conscious decisions not to assume the caregiving role. Larkin (2008) concluded that many caregivers felt that they did not have a choice about undertaking (serial) caregiving roles because of familial obligations to parents, siblings, spouses/partners. Pre-existing relational ties may automatically render a person a carer whether or not they are able to perform that role (Payne, Smith and Dean, 1999; Payne and Ellis-Hill

2001). Caring about a terminally ill person is taken as the basis of caring for, blurring boundaries between nursing and social care, redrawing formal and informal, professional versus family caregiving division of labour (Exley and Allen, 2007). Families provide care for many reasons, including cultural expectations, preference for avoiding institutional care, and attachment. Increasingly it is accepted that dependent people will be cared for in the community by family members and significant others and that dying at home is the preferred choice of most terminally ill people (Harding, Higginson, Leam, Donaldson, Pearce and George, 2004; Harding, 2005; Ingleton, Payne, Nolan and Carey, 2003; Payne et al., 1999; Skilbeck, Payne, Ingleton, Nolan, Carey and Hanson, 2005).

Background

Care for terminally ill people at home results from a convergence of social, philosophical, policy and economic shifts in health policy (see, for instance, Bachner, 2007; Exley and Allen, 2007; Payne and Ellis-Hill 2001). The use of the term 'home' is as a concept as well as a physical place, denoting expectations of emotional, social and physical security and comfort (Hera, 1995). As the funding emphasis moves from in-patient institutional care in hospitals and hospices, to home care, the central tenet has been the use of lay people as co-providers of health services (Exley and Allen, 2007). Heaton (1999) attributes the term 'community care', to Bayley (1973), a term which came to mean not only care in the community but care by the community. Hospitals and hospices reduce the length of admissions to shorter stays which focus on symptom management, respite care, or end of life care rather than long term care (Ingleton et al., 2003; Harding, 2005). The advance of informal or family caregiving coincides with the retreat of the welfare state model of comprehensive health and welfare provision (Exley and Allen, 2007). These changes in policy described in political terms as "health reforms" in many western countries, mean that increased numbers of palliative care patients receive the majority of their

care at home. Writers on this topic (see Aranda and Hayman-White, 2001; Di Mola, 1997; Milne and Quinn 2009) attribute the increased responsibility of family carers and the psychological and physical costs that these families experience, directly to health reforms. “.. ‘hospital/ hospice at home’ emerged out of the problem of increasing pressure on hospital beds- a factor that is often overlooked in discussion about the idea of ‘home care’ ” (Di Mola, 1997:131). Families are encouraged to become primary caregivers, chose to undertake the role, or discover that they have no other option than to do so (Bernard and Guarnaccia, 2002; Payne et al., 1999). “In reality many relatives take up the care-giver role either by default, as no-one else is able to provide care, or at a time of crisis” (Payne and Ellis-Hill 2001:10). Young, notes ... “home care requires families’ cooperation, who, since they face the absence of any alternative method of care that is decent, seem to have very little choice in the matter” (1981:6)

Thus, home palliative care would be impossible for many people without the support of caregivers (Palliative Care Australia, 2004). Many of the duties are undertaken by these family caregivers with little preparation, by persons whose usual life roles are not related to health care (Aranda and Hayman-White, 2001). For some carers, not only is the caregiving role assumed but also may be the first exposure to death or dying. While death, dying and bereavement are natural, personal and social processes, people often have little experience of them (Reith and Payne, 2009). The provision of care by family caregivers enables the terminally ill person to remain at home.

Care at Home

In New Zealand most people with palliative care needs die at home (The New Zealand Palliative Care Strategy, 2001). This move is not only fiscally driven but influenced by humanitarian movements such as hospice, which sees the family and the patient as the focus of care. The ‘caring’

philosophy of hospice encourages family participation in the care of the dying; a holistic approach which considers the social, spiritual and emotional quadrants of each individual to be of equal value to the physical quadrant. "...Hospice work reconciles the discipline of applied science with the philosophy of personal care" (Saunders, Summers and Teller, 1981: viii). Within the holistic philosophy of palliative care, McLeod (2008: a) summarizes the complexity of the caregiving role; one that has behavioural and motivational elements, physical manifestations accompanied by psychological, spiritual and social dimensions. Hospice care is underwritten by principles and beliefs which stress that death and dying are normal and natural; palliative care "affirms life and regards dying as a normal process" (World Health Organisation, 2002 definition). "Good care" becomes not only about "good medical care". This 'de-medicalisation' of death and dying in the latter part of the twentieth century suggests that familiarity of the home environment, improved quality of life for the terminally ill person, and greater autonomy of the patient and family has returned the preferred place of death to the home. Home has resumed its ancient role as a place to care for the sick and the dying (Di Mola, 1997).

Time – 'temporality'

Concurrently, medical and pharmacological advances in cancer treatments and those for other life limiting illnesses, have not only reduced disease spread, but have prolonged the life spans of those with terminal illness, or prolonged illness trajectory where patterns of dying are uncertain (Bernard and Guarnaccia, 2002; Thomas, Morris and Harman, 2002). This lengthening of life due to improved treatment regimes also lengthens the period where the patient is dependent on others: informal caregivers within a cancer context are more likely to provide more complex care for a longer period of time (Nijboer, Triemestra, Tempelaar, Mulder, Sanderman and van der Bos, 2000). Long term care in a care facility had been redefined as social rather than medical care, shifting the financial costs of

care from governmental funding to social care and from social care the move to personal responsibility is the next shift in the continuum.

Such social, fiscal, policy and treatment trends continue to emphasise care at home with informal family members providing the care, despite the changing social, geographic and family patterns. The changing role of women, the later age of first or subsequent partnerships or marriage, increased geographic mobility, reduction in traditional family composition with more one parent families and more people living alone, all have an impact upon the availability of family caregivers to undertake care of a terminally ill family member (Exley and Allen, 2007; Payne and Ellis-Hill 2001). Further challenges in caring for the dying at home are the changes in the nature of the relationship between the carer and the cared for wrought by the caregiving process.

Relationships – ‘relationality’

Strong emotional or social attachment is assumed to underpin the caregiving/cared for dyad. However, the very relationship which propels the role of caregiver is changed and challenged as a consequence of caregiving: a partner may cease nurturing the partnership relationship during the stress of becoming the ‘nurse’, the adult child caregiver may perform tasks for the older person that were once provided by the parent. The relationship is further challenged if the cares are associated with inflicting pain, such as moving or washing the terminally ill person. The undertaking of personal cares may damage the very relationship that it seeks to revere as the nature of the relationship between the caregiver and the ill person changes (Exley and Allen, 2007). The family is both the principal source of support and care and also the unit that faces the illness. The strain experienced in undertaking the caregiving role has been referred to as ‘caregiver burden’. This all encompassing term refers to the financial, physical, emotional, psychological and social/spiritual effects of caregiving. Ingleton, Payne, Nolan and Carey,(2003) suggest that the

terminology of 'caregiver burden' assumes no reciprocity in the relationship, or that the caregiving is unrewarding. The relief of this 'burden' is by applying a therapeutic model in which the professionals are perceived as the expert. However the burden model of care is contested within the context of palliative care.

Labour – 'corporeality'

One manifestation of the caregiver burden is the duality of physical caring and emotional labour. The dynamic interaction encompasses both the physical work of caregiving and the social, relational work of caring. The former is objective, quantitative, that is, performing functional or instrumental tasks. The latter is subjective, that is, the emotional stressors associated with an acute awareness of comfort for the ill person and of the impending death. The term 'emotional labour' is borrowed from a 1970s study by Hochschild (1983) which describes the effort made by individuals to manage their own feelings and those of others within a work setting. Demands on carers stem from a variety of sources, most notably the practical and emotional work that they must perform (Rose, 1998). Carers are reported to sublimate their own needs (Cole and Gucciardo-Masci, 2003; Exley and Allen, 2007; Thomas et al., 2002) at times perhaps holding their own emotional distress as they undertake the care. This care is undertaken in the presence of witnessing suffering or distress and observing the progress of a disease as well as negotiating communication on what could be viewed as difficult and awkward topics (Rentmeester, 2007). Terms such as 'caregiver burden', 'caretaker role fatigue', 'spousal burnout' and 'role engulfment', 'carer fatigue' refer to an imbalance between the physical and mental resources required in undertaking the care of someone with an illness in their own home. This construct of burden rather than privilege is a noted feature of general caregiving literature; palliative care literature puts greater emphasis on privilege.

Home - 'spatiality'

Home care presents challenges not only in the relationships, but also the physical environment. Home is where many people feel truly themselves; home is perceived to be the centre of a person's life and closest relationships (Di Mola, 1997; Exley and Allen, 2007). Home is not merely about the physical space but the emotional and social relationships. The work of caring for someone in their own environment is predicated on the existence and establishment of intimately social relationships. When care work is relocated to the home, there occurs a fundamental change in the meaning of 'home'. The environment changes with the introduction of 'industrial' health care equipment, most homes are not designed to meet the needs of ill people (Rose, 2001). The function and meaning of living spaces change to accommodate a person with reduced mobility, re-drawing the boundaries of the nature and aesthetics of 'home'. The introduction of hospital equipment symbolizes the 'nursing' nature of the caregiving work, and thus the physical and emotional labour entailed in caring for a dying person. The private becomes public. The boundary between family and the outside world becomes more permeable (Altschuler, 2005). Health professionals who visit for the amelioration of symptoms may not only be intrusive but also learn and hold many aspects of family life previously deemed private (Cantwell-Bartl, 2006).

Definition of terms

Family: includes a status derived from biological fact and/or people bound together by mutual commitment and/or care (Englehardt 2007). Kovacs et al., (2006 :15) use the definition provided by Lattanzi-Licht, Mahoney and Miller (1998) "all those in a relationship with the person who is dying, people who can be counted on for caring and support regardless of legal ties", inclusive of families of choice as well as birth families. This definition reflects the increasing diversity in family types. In the study which looked at family responses to life limiting illnesses, Waldrop, Milch and Skretney

defined "family as either relatives or people in close or intimate relationships" (2005: 89).

Caregiver: defined as the principal person who provides substantial emotional and caretaking support for the terminally ill person. There remains the debate in literature as to whether caregivers ascribe this term to themselves or whether this term is used primarily by professionals. Caregiving can be seen as a dynamic ongoing process for which there may be several trajectories (Nijboer et al., 2000); the defining moment being when the caregiver perceives the role was assumed. The construct refers to the physical, psychological, financial, and social experiences specific to the care demands and is a relational concept. Relational in that there can be no 'carer' without a 'cared for'. Heaton (1999) emphasizes that which would appear to be clear in any definition of a group of individuals, namely that carers are not one homogeneous group and that the definition itself is varied and contested in nature. Carers are emotionally, morally, culturally, and financially bound into the role, which includes facets of obligation and reciprocity (Schofield, 1999). Caregiving is socially constructed and carers are positioned by gender, race and kinship expectations (Schofield, 1999). The chapter by Lee in Payne and Ellis-Hill (2001) reports on gender inequalities; that both cultural and social factors determine that the majority of family caregivers are women. The National Institute of Clinical Excellence (NICE 2004) states " carers who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management" (cited in Payne, 2007: 84).

Commentary of definition

The term 'carer' emerged in the 1970s (Heaton, 1999; Ellis-Hill and Payne, 2001). In the following decades, the term continued to be generated by health professionals to describe individuals, usually family members or those with a pre-existing relationship with the ill person, who provide

unpaid assistance and support for a person dependent on others due to illness or disability. The extent of this support, as well as the level and degree of care is often unclear. The genesis of the term 'informal carer' appears to be derivative of the work carried out by health professionals, defined in terms of nursing activities or physical work. Formal or professional care, due to the fact that it was a profession, was seen as more desirable. The 'secondary tier' of care that is provided by unpaid and untrained carers generated the terms 'family carers', 'lay carers', 'home carers' and was associated with 'caregiver burden'. Twigg and Atkin (1994) suggest that health professionals classify 'caregivers' in four different ways, each serving the needs of the professionals or the agencies they serve: as **resources** the carer is seen as free provider of primary care; as **co-workers** carers are seen more as joint providers of instrumental care; as **co-clients** with needs of their own; and as **superseded** where the health professional attempts to reduce the barrier between 'cared-for' and 'carer' by promoting the independence of both. Nolan (2001) and Nolan, Grant and Keady, (1996), whilst not challenging the use of the term, challenge the burden construct.

Professional literature employs the word "caregiver" or "carer" to describe those who provide help on a formal, paid, occupational basis, such as professionals, as well as informal caregivers such as family, friends, partners who have a personal connection with the terminally ill person (Kovacs et al.,2006). In the context of this thesis, caregivers are 'informal' caregivers, the caring "not having been carried out on a professional basis, and, excluding benefits, was unpaid" (Larkin 2008:4). Assuming a caregiving role may be a gradual process, and like any process, defining when it began may be camouflaged. The language of Lewis encapsulates this concept of gradual transition, of changes not really observable. "There was no sudden, striking, and emotional transition. Like the warming of a room, or the coming of daylight. When you first notice [it has] already been going on for some time" (Lewis, 1961: 52).

A small but increasing body of research focuses on stress and coping and adaptation in end of life caregivers (Allen, Haley, Roff, Schmid and Bergman, 2006). The focus of this research moves away from the deficit model, and like contemporary bereavement research reduces the pathology of the experience of caregivers and aims at developing models for resilience.

New Zealand Context

In the contemporary New Zealand context both the terms 'carer' and 'caregiver' are used. For instance, the Ministry of Social Development's 2008 publication is titled "The NZ Carers' Strategy and Five-year Action Plan". This is a policy document based on the previous consultation document, 2007, entitled "Caring for NZ Carers: your life, your work, your say". Hospice New Zealand employs the alternative 'caregivers' in the undated publication "A Guide for Caregivers: a booklet for those whose loved ones are living with a terminal illness". In other hospice literature (for example, South Auckland Hospice Charitable Trust's 'Helpful Hints') the term 'carer' is employed.

Some New Zealand caregiver research has emerged in the last decade: Hale (1999) reported on the caregiver's identity reflected through changes in language and networks for long-term carers. A research report commissioned by Carers New Zealand evidenced carer dissatisfaction with lack of information, lack of knowing how to care and lack of knowing how to do the right thing (Jorgenson, 2009). Janet McDonald (2008) reported on young carers, those aged between 14 and 25 years who undertook caregiving or assisted with caregiving for a family member with a disability. The Carers New Zealand report, like the research by Hale(1999) and by McDonald (2008) is generalized across all areas of caregiving. Caregiving in New Zealand was identified as riven by a range of difficulties. Other key areas identified in New Zealand caregiver research are funding, and whether the supports including financial support sit within the health or the

welfare system. Access to benefits, respite care provision and entitlement, accessing systems and support all present as obstacles to those in a caregiving role.

Literature search

A review of relevant caregiving literature in the context of terminal illness reveals that only a limited amount has been published. The International Association for Hospice and Palliative Care address this issue in their online newsletter (August 2009), where it is estimated that up to 50% of papers relevant to palliative care clinical practice may not be captured, citing data are not concentrated in the few specialist palliative care journals or bibliographic data bases. Many papers are not themed or titled as palliative. As a result they will not be immediately obvious (<http://www.hospicecare.com/news/08/90>). In order to obtain articles, the literature search I employed used the key words: cancer, terminal illness, family caregiving, care* and palliative care. Of the articles found, those specific to caregivers within a terminal illness context were reviewed. The diversity of journals in which core hospice and palliative care literature is published remains a challenge (ibid). For this reason data base searches were supplemented with manual searches of journals and books, reviewing references from identified material including searches of key authors in the field of palliative care, bereavement and caregiving. This resulted in specific articles on caregiving in a palliative care context and in the wider context of this thesis, those articles which analyzed both caregiving and the bereavement of those caregivers. Another method employed was literally browsing shelves at the medical school, university and hospice libraries, limiting my search to recent international palliative care journals, those publications dealing with the ethical issues surrounding death, and allied health publications. By this maverick method, I discovered articles that would have been outside the usual key work search, but proved relevant to the overall tenor of this work.

Assessment tools

Most caregiving publications address the issues of caring for populations such as the elderly, those with dementia and people with physical disabilities. Within this realm of caregiving, some of articles sourced employed the use of specific tools to assess the physical burden of care on caregivers. The Caregiver Strain Index (attributed to Robinson 1993) is a tool that measures strain related to care provision, most generally used to assess individuals who have assumed the role of caregiver for an older adult with co-morbidities and/or dementia. The CRA, Carer Reaction Assessment Scale (see Bachner, O'Rourke and Carmel, 2007) although used by Nijborer et al. (2000) to assess the needs of partners of colorectal cancer sufferers, is a tool primarily used to assess the burden of caregivers of those with dementia and does not apply within a specific palliative care context. Other literature reviewed was aimed at assessing carer's needs, their satisfaction with support, or with evaluating the informational needs of carers. The key features of such assessment scales or measures are their focus on the instrumental tasks. One advantage is that results yield quantifiable data making possible comparison with other studies, although such assessment scales tend to focus on and measure the more negative aspects of caregiving (Payne and Ellis-Hills 2001). However, within a palliative care context the functional or instrumental tasks are reported to be secondary to the emotional stressors (or Hothschild's term, 'emotional labour') associated with an acute awareness of impending death.

Functional tasks are skills oriented, quantifiable, observable and measurable. They include the amount of time spent on physical work undertaken in the caregiving role. Such tasks are often around physical comfort of the patient: pillow arrangement, washing and toileting demands, administration of medications and other physical cares. These are generally categorized as personal and domestic support (Payne and Ellis-Hill 2001). Measures of these tasks alone do not appear to be indicative of the burden of care experienced in caring for a dying person.

Of greater importance is the concept of subjective burden, a term that I employ is 'the mantle of responsibility'. This includes the ways in which a caregiver provides emotional, psychological and spiritual support. This support is complex: it affirms meaning, accommodates changing roles, facilitates decision making, negotiates relationships with health professionals and the 'emotional labour' as detailed previously in this chapter. Nolan (2001), concludes that the less visible aspects of caring are the least well recognized and are the most difficult to accomplish well. One difficulty encountered, but not mentioned by the participants in this study is the invisibility of caregiving. Any undertaking that occurs in the background has a limited visibility. Caregiving, with the focus on another, occurs in a background sense. Equally, tasks or duties done well are often invisible precisely because of the competence demonstrated. Thus caregiving is comprised of the two constructs - the dual function of instrumental tasks, 'doing for' and the emotional work of 'being there'. Katz and Sidell (1994) engage in the discussion of what support means. Three constructs seem to emerge, predicated on the components of caring for and caring about. Emotional or affective support entails involvement and intimacy, requiring warmth, affection and companionship. Cognitive or informational support is about providing advice and information on a whole range of issues. Instrumental support, as is self evident, entails actually doing something such as cooking a meal etc.

Burden vs. Privilege

Although general research has focused on the stress of caregiving, that is the 'caregiver burden', the palliative care caregiving literature and my own experience as a palliative care social worker does not indicate an exclusively negative experience (Palliative Care Australia, 2004; Ingleton et al., 2003; Nolan, 2001; Salmon et al., 2005). There is a danger of labelling caregiving as completely burdensome if the focus is on the constraints and stressors experienced by a caregiver, using a 'pathological' model of family care (Twigg and Atkin in Nolan, 2001). As discussed this construct is used

more readily when the caregiving role is undertaken for someone with a debilitating but not life limiting condition. The next section moves from the literature on caregiving as a general construct, to the specific issues in caring for a dying person.

Caregiving within a Palliative Care Context

“Caring for people when they are dying will always be one of life’s most challenging privileges” (Kovacs et al., 2006:25). There remains in my mind a question as to whether the “burden” construct of caregiving, often applied to those caring for the frail, cognitively impaired, (those with dementia specifically) chronically ill or elderly, or parents caring for children with disability, is equally applicable to those caring for another at the end of life. Caring for the terminally ill does have unique features: profound interpersonal and caregiving complexities, acute medical changes and disease unpredictability set this arena of caregiving apart from long term care for someone with, say, dementia. In palliative care the backdrop to the caregiving role is the anticipation of impending death and the end to the caregiving role.

The recognition that terminally ill people have a limited life expectancy is a criterion for entry into a palliative care service. Brevity of remaining time and the transitions that occur bring with it a sense that there is no second chance to ‘get it right’, that the experience cannot be altered or repeated (Payne and Ellis-Hill, 2001; Lowery, 2008). Caregivers, as noted previously, put the needs of the terminally ill patient above their own which leads to the moral imperative to provide the best possible care. Strang, Koop and Peden (2002) record the experiences of family caregivers, as a ‘singular experience’, as though living in an unreal, suspended cocoon-like world. This experience is also reported as occurring within a concertina-ed time frame, where there is limited time to gain new (caregiving) skills or develop new strategies to manage the changes that occur with the

terminally ill person (Harding et al., 2004). Limited time equally leaves less time to adjust to the losses.

Caregivers experience rapid loss prior to bereavement (Pierce, 2006). If the changes are especially rapid, such adjustments are more difficult to accommodate. Symbolic losses such as position in the family or role redefinition sit alongside the very real losses of appearance, cognition and functional ability. The term 'anticipatory grief' or 'anticipatory mourning' recognises that grief plays a significant role long before the actual death (Doka, 2000; Rando, 2000). It is a term that has come to be used to describe the grief process of individuals who are losing someone slowly, incrementally and expectedly. The term derives from work undertaken by Lindemann in the 1940s that recognised that grief can be and is felt before and after the time of death. Caregivers experience grief not only on the death of the terminally ill person, but along the journey of the illness as they strive to manage the multiple and incremental losses of someone who is physically and/or emotionally dependent on them (Ross, 2008). During the time of anticipatory grief, a caregiver not only prepares for a life following the terminally ill person's death, but acknowledges the 'mini losses' along the way (ibid). The losses may include such things as the loss of future goals or plans; loss of companionship and intimacy; loss of assistance with daily domestic tasks; the loss of a life style, both socially and economically. The loss for the caregiver may also be their own loss of independence or autonomy for the period that the caregiving role is undertaken. This grief experience encompasses the complexity of losing an individual who has had an impact the caregiver's daily life. It should be noted that there is academic debate as to the existence of anticipatory grief, whether it eases the grief of bereavement or whether it could in itself be seen as grief (Reynolds and Botha, 2006). In the context of family caregivers, however, there is no debate that the expectation of death and the incremental losses experienced by caregivers are significant in the palliative care setting.

Overview/Chapter Summary

In conclusion, this chapter has provided an overview of the generalized caregiving literature with its construct of 'burden', and the sparse literature on caring for someone with a terminal illness. There exists a duality in the meaning of caregiving for a terminally ill person. Previous research describes two contrasting constructs that shape the identity of the caregiver: burden and privilege. The caregiving period in terminal illness is, by definition, likely to be shorter than for a chronic or dementing illness. However, the losses experienced over a shorter period of time prescribe that the changes require adaptation in a foreshortened frame.

Caregiving in the palliative care context is underpinned by the notion that the caregiving role will end on the death of the terminally ill person. For family caregivers, the same people who have provided the care are the ones who are bereaved. This transition is not one widely recognized in the academic literature (Hudson and Payne, 2008). Palliative care does not end with the death of the patient; it extends to continuing support for family, relatives or caregivers (Payne et al., 1999). This chapter therefore ends, looking toward the next section, bereavement in Chapter 3.

CHAPTER THREE

BEREAVEMENT

**But when he's gone
Me and the lonesome blues collide
The bed's too big
the frying pan's too wide.**

**Joni Mitchell,
My Old Man, 1970**

Bereavement

Introduction to concept

It has been argued that the truly personal experience of loss and grief cannot be encapsulated by grief theory alone (Payne and Rolls 2009). Many fiction works, both contemporary and classics, are clearly narratives of loss, separation and bereavement. These narratives detail not only stories of personal loss; they also “distinguish between *whom we have lost* and *what we have lost in them*”(Leader, 2008: 34, italics original). Grollman in a presentation noted that when one loses a parent, one loses a link with the past. When one loses a partner one’s present is challenged. When one loses a child one’s future is altered (Doka, 1993). It could be noted that loss and grief weaves its way through the course of life.

In this chapter I introduce key loss and grief theories and the way these both influence and have been influenced by academic and therapeutic paradigms. As well as reviewing bereavement literature and the progression of thought in 20th and 21st Century grief theories, this chapter will provide a definition of terms and give an overview of bereavement. I conclude with an investigation of grief responses, explore other terminologies currently in usage in grief literature and discuss the validity of bereavement risk assessment tools.

My understanding of grief has been shaped by reading grief theories and by speaking with bereaved people as the palliative care hospice social worker coordinating the bereavement programme. That bereavement support is available to the family is a central tenet of palliative care and has been explained in the first chapter of this thesis. Care of the family following death is one of the underlying principles of hospice work.

Background

Different models of bereavement have been developed to explain the often confusing range of emotions that comprise the experience of grief. Parkes (2006) distinguishes between models which describe and categorize observed phenomena, and theories which attempt to explain and find causes. According to Hera, theory is a set of principles for explaining what is; a tool which helps us to examine and structure beliefs and understanding; a way to make sense of experience (1995:4). Grief theory has both had an influence upon and been influenced by theorists who work with bereaved people. Walter (1999) addresses two issues when considering the place of the dead and the place of the bereaved. The bereaved are placed between the living and the dead, and Walter notes that there is a binary position, integration of the dead or moving forward without them.

.. the living must leave the dead behind and move on without them. The other is that the dead are always with us and the bereaved continue to bond with them; indeed the dead must be incorporated in some way if families, other groups and indeed entire societies are to have any sense of their past. Popular culture in this, (*ie the 20th Century*) has affirmed both views. (Walter, 1999:205)

The introduction to this thesis canvassed death and dying in more depth (p 9). This chapter has bereavement as its focus. Payne and Rolls (2009) suggest that there are three overarching theoretical perspectives into which Western constructs of grief fit: (1) psycho-analysis and attachment theories, (2) stress and coping theories and (3) continuity theories. It is useful to now turn to these three broad categories, detailing them, reviewing the literature and finally concluding the place of such theories when considering grief within the context of caregiver's bereavement in a palliative care context.

Grief theory

Psycho-analysis and attachment theories: Contemporary bereavement studies are increasingly challenging the previously accepted construct described by Freud (1917), where grief is a loss from which the survivor is expected to 'recover'. As a founder of the psychoanalytic school, Freud's discipline was psychiatry. Freud (1917) wrote of mourning as taking place over a long period of time, but the "resolution" of grief was evidenced once the bereaved person had completed emotional detachment from the person who had died. Attaining this detachment was the goal, although "grief work" was a life long process. In this paradigm mourning is often equated with the idea of getting over a loss (Leader, 2008). The thoughts discussed in Freud's *Mourning and Melancholia* (1917) provide the basis for current theories of grief and the requirement for resolution. "Grief work" was the exploration of intra-psychic processes, which was accessed through talking/counselling/therapy. Failure to engage in this "grief work" was 'abnormal', thus pathologising those responses which did not fit into the psychoanalytic construct. The late 20th Century theorists, for instance, Stroebe & Schut (1995) and Walter (1999) questioned the previously held notions of normal and the antithesis, pathological grief, emphasizing instead that the variety of ways, cultural lore and individual expressions of grief were now the 'new normal'. Some four decades following Freud's seminal work on mourning, the well known Swiss born American psychiatrist Dr Elizabeth Kübler-Ross continued to view mourning through a psychoanalytic construct.

Dr. Elizabeth Kübler-Ross (1969) worked with terminally ill patients within an American hospital in her role as psychiatrist. Her writings describe the 'stages' of dying: denial, anger, bargaining, depression and acceptance. In the work, "On Death and Dying" (1969), the five stages comprise only a small part of the book's contents. The five stages are described yet there is a failure to distinguish clearly between what does happen and what should happen. The classifications of grief may well have been within the social

context of mid twentieth century. There are elements of description in the five stages, although they remain fundamentally categories into which experience is boxed. The ideas became popularist and the descriptive became prescriptive. The detail of Kübler-Ross's stage theory will now be examined, precisely because of the popular appeal and widespread level of acceptance that the stages have achieved. These ubiquitous, prescriptive stages relate to the adjustments she identified that people make as they face their own impending death. The stages construct has been applied to bereavement, where the frightening but normal range of emotions is made manageable by neat, linear sequences through which every bereaved person must pass in order to "recover" from bereavement. There remains debate whether the 'stages' could be equally applied to the bereaved as to the terminally ill. Into this academic argument I suggest that later works of Kübler-Ross explicitly state that the families pass through these same stages either prior to or after the death and that families need to re-experience the stages a second time after death (1974: 104). In the 1974 work, the prescriptive becomes even more definite, with its inherent impulse to get through faster or to at least be 'on schedule', the word 'stage' implying a time component. There is a sense of movement through the stages as though the destination holds more importance than the journey and that the 'recovery' returns the mourning person to their pre-mourning state. The five stages of grief are worth a closer examination as far as they relate to bereavement. The first, (1) denial, is typified by a sense of disbelief, that some mistake has been perpetrated, and it's 'all a bad dream from which I shall wake up'. The emotional response could be described as a temporary state of shock and a healthy way of temporarily dealing with an uncomfortable and emotionally or spiritually painful situation. This period acts as a buffer allowing the person to collect him or herself to mobilize less radical defences. (2) Anger looks to blame another, or alternatively, that what is occurring, should not be occurring to **me**. (3) Bargaining indicates the desire to feel a sense of control over a process that feels uncontrollable - the sense that there must be some way a

grieving individual can change the course of events. The fourth, (4) depression occurs when hope is lost, and is accompanied by feelings of anguish, guilt, helplessness and despair. Whilst many of the emotions of grief mimic the symptoms of depression there is clear medical literature which notes that a diagnosis of clinical depression is not indicated in the first year of bereavement (McInnis-Dittrich, 2005). This assessment is endorsed by Leader, "The concept of depression is complex, and has its' genesis in the human narratives involving separation and loss" (2008: 3). The final stage of (5) acceptance is far from passive resignation and may in fact be devoid of all feelings. Kübler-Ross recognized the multitude of emotions felt by grieving people and legitimized the full expressions of the emotions. These descriptors/prescriptors in the view of Leader are classed as surface descriptions of behaviour rather than a deep exploration of the changes in the unconscious mental life of the bereaved individual. It could be argued that the use of categories is the Western world's way of ordering or owning the natural world, "nature is the enemy of humanity and needed to be brought under control" (Maitland, 2008: 230). Continuing this school of understanding of grief, the third theorist, Worden worked within the psychoanalysis and attachment paradigm borrowed from earlier Freudian works.

William Worden (1982, 1991), Professor of Psychiatry at Harvard Medical School outlined four "tasks" of mourning, rather than "stages" or "phases". These are: the necessity to accept the reality of the loss, to work through the grief by experiencing the pain, to adjust to the environment where the deceased is missing and to emotionally withdraw from the deceased thus investing in new relationships. In the second edition (1991) of the same title, Worden revised the final task to emotionally relocating the deceased in order to move on with life for the survivor.

The "stage", "task" or phase approaches culminate in the desired outcome, which is "resolution" or "acceptance" and are based on the assumption

that grief is a process in which there is an outcome. This implies that there is an end to grieving and that health professionals can assist the bereaved person in “completing” the grief work. In contrast:

I thought I could describe a *state*; make a map of sorrow.

Sorrow, however, turns out to be not a state but a process.

It needs not a map but a history. (Lewis 1961:50)

Models, such as those employed by Worden and Kübler-Ross were strongly influenced by attachment theory and were developed to describe the experience of people who were bereaved. They were also widely applied to those who had experienced non-death losses (Quinn, 2005). Contemporary theorists have questioned the validity of the “stage” model, noting the linear and sequential model does not reflect the experience of grieving people, that emotions occur concurrently, non-sequentially and that all the emotions described may not be experienced (Friedman and James, 2008). Lewis puts it like this “... in grief nothing ‘stays put’. One keeps on emerging from a phase, but it always reoccurs. Round and round. Everything repeats...” (1961:49). The benefit of linear stage theories is the structure they give to helping professions (and indeed to the bereaved themselves who search for a benchmark); a framework during a process that is fluid and highly individualized, that of grieving. By the mid 1990s this prescriptive model of working with bereaved people was challenged by Stroebe and Schut (1995), with their Dual Process Model. The theories developed since the mid 1990s have assisted in conceptualizing the nature and extent of losses and are a departure from the psychoanalysis and attachment theory paradigm. Theories of grief have evolved leading to the observation that grief is not an illness from which people recover, nor are those who grieve passive - “grieving is something we do, not something done to us” (Neimeyer, 2008 a).

Stress and coping theories: Stroebe and Schut’s (1995) “Dual Process Model” (DPM) suggests that in grieving there are two processes or

orientations experienced, one toward loss, the other toward restoration. Healthy grieving is about moving ("oscillation") between these two in culturally appropriate ways. During the loss orientated process, the bereaved person considers and expresses the loss. At other times, those of restoration, the focus is on rebuilding the present and the future and expressions of grief are contained. Oscillation also describes the process of moving between avoiding and confronting these dimensions of loss. Both orientations are necessary for adjustment. The suggestion is that over time coping responses become more progressively 'restoration' focused as the intense and consuming pain of grief is ameliorated. The Dual Process Model concentrated on emphasizing a bereaved person's capacity to integrate stress, coping and resilience, and was readily accepted by palliative care practitioners as offering an approach which matched with observations in practice. The DPM theoretical position is derived from psychological literature on cognitive processing, identifying the role that stressors have in triggering either an emotional response or a cognitive appraisal of the stressor, the primitive 'fight or flight' response.

Whilst this model can better account for cultural and gender differences, it remains psychological rather than social in its construct. When the needs of the bereaved are framed in psychological terms, the focus remains primarily on the inner life of the individual. The Dual Process Model incorporates a sense that restoration means not a return to the pre-death way of living but to a new way of living with the loss. In this paradigm acknowledgement is made of practical tasks that need to be undertaken in coping with grief, in attending to life changes and changing social roles and relationships as well as the emotional grief work. The belief in the importance of meeting grievers on their own terms is highly congruent with values held within palliative care. A further departure from the psychoanalytic and attachment paradigm or the stress and coping model was developed by Klauss, Silverman and Nickman, (1996).

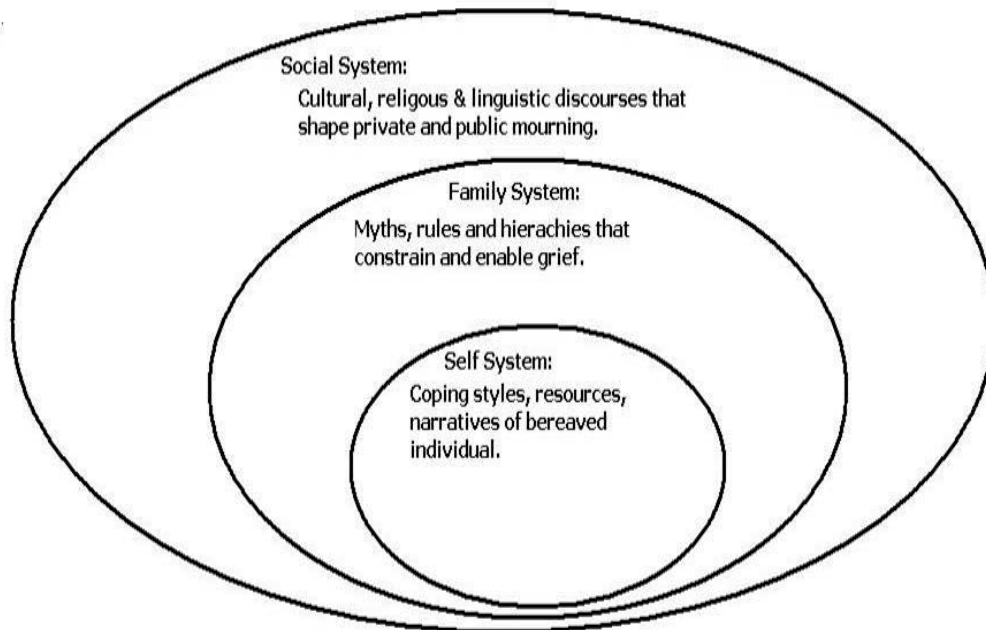
Continuity theories: Klaus et al., (1996) presented a “new model of grief” seeking to acknowledge and build on the then emerging consensus among bereavement scholars, suggesting that knowledge of the grief process be expanded. Bereavement scholars recognized that the existing paradigms were based on Western psychoanalytic thinking and did not include different sorts of losses or cultural or gender differences in expression of loss. The writings of Klaus et al., (1996) described the “continuing bond” between the survivor and the person who has died. This bond acknowledges that the relationship between two people is not completely severed at death (or “detached” as Freud would have it) but continues in some new form by way of emotional or memory legacy that the deceased and the survivor share. In this way the meaning of the loss is negotiated and renegotiated over time rather than a process of “resolving” the loss.

Walter (1999) brought a sociological analysis to grief theory, suggesting that rather than severing the attachment bond with the deceased, the bereaved instead integrated memory of the person who had died, thus allowing an ongoing connection or bond. Walter argued that such narratives or in his terms, the integrated biography of loss, is socially constructed, emphasizing not the intra-psychic nature of loss but the social, cultural and interpersonal aspects of bereavement. The biography of loss is an underlying theme in the writings of Neimeyer (2006).

Neimeyer (2006; 2008(a); 2008(b)) contends that grief therapy is about making meaning within and between people; intervening in and the reconstruction of meaning and the continuing bond. Thus, grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by loss. As a cognitive constructivist, Neimeyer posits that grieving entails an active effort to reaffirm or reconstruct that meaning. Meaning reconstruction therefore is a key process in bereavement adaptation. Neimeyer contends there are four broad classifications in

response to bereavement. (1) Resilient survivors - who do not demonstrate profound distress because of the capacity to assimilate the loss into an existing stable view of the world (meaning system). (2) Adaptive grievers - who ultimately accommodate their narrative to the changed reality after wrestling with existential or practical questions. (3) Foreclosed grievers also accommodate the loss, but into a worldview that is essentially pessimistic which reaffirms a sense of meaninglessness. (4) Chronic grievers experience invalidation of their world view, that is, experience difficulty in reconstructing meaning in their past losses, present circumstances and changed future. This framework acknowledges the place of resilience and adaptation for some, recognizing that others experience a chronic inability to make sense of the losses.

Those theorists within the continuity paradigm are informed not only by psychological constructs; other disciplines now inform the discussions and development of grief theory. Continuing bonds encompass a diversity of cultural, linguistic and religious discourses. In various cultures this may be expressed as filial piety, whakapapa, living memorials or continuing bonds. Theorists who work from this model acknowledge that the form and function of the grief changes over time. The model of influences upon grief is adapted from Neimeyer (2008(a)).



Another metaphor used is that of an individual “growing around their grief”. This model was described by a bereaved partner who saw their own grief as visually as, say, the size of a melon. During the months following the death, this ‘melon sized grief’ filled the bereaved person’s whole world. That is, diagrammatically, the bereaved experienced their life to be the same size and shape as their grief. The bereaved person imagined that the ‘size’ of their own grief would shrink with time. However, what was experienced was not the ‘size’ of the grief diminishing but the boundaries of their own life expanding around it, giving the sense that the grief was ‘smaller’*²

² There is no reference for this model. It is used with the permission of the client of Mary Potter Hospice who first coined the term

Definition of terms

Bereavement is the situation of a person who has recently experienced the loss of someone significant through that person's death (Stroebe and Schut cited in Hockey, Katz and Small, 2001:4). It is the long period in which the survivor must learn to cope with the loss. Bereavement refers to the objective state of having lost something or someone or being bereaved or deprived of another (Walter, 1999).

The term bereavement refers to the state of being bereaved or deprived of something; that is, bereavement identifies the objective situation of individuals who have experienced a loss. Both the noun *bereavement* and the adjective bereaved derive from a less familiar root verb, *reave*, which means 'to despoil, rob or forcibly deprive'. In short a bereaved person is one who has been deprived, robbed plundered or stripped of something. (Corr et al.in Hockey et al., 2001:5)

Bereavement is the state of "being caught between the present, a past and a lost future" (Walter, 1999:70).

Grief is often recognized as an activity and is a normal reaction to a loss and change (Hockey et al., 2001; Parkes, 2006). It is the internal and external reaction to the loss (Hockey et al.,2001) or when the individual processes deep feelings of sadness, abandonment or loneliness. Grief is generally described as the adaptive, cognitive process of dealing with loss, disappointment and change (Pierce, 2006).

Grief is the *response to loss*. When one suffers a loss, one grieves. The word *grief* signifies one's reaction, both internally and externally, to the impact of loss....The tem

grief is often defined as 'the emotional response to loss'.
(Corr et al. in Hockey et al., 2001:5)

Mourning usually refers to the cultural, linguistic and religious discourses that shape private and public mourning; the prescribed process of coping with the loss and grief (Hockey et al.,2001), the expressions, behaviours or acts of grief that are socially and culturally sanctioned, the behaviour that social groups expect following a bereavement (Walter,1999).

Mourning refers to the social expressions or acts expressive of grief which are shaped by the practices of a given society or cultural group. (Strobe and Shut, in Hockey et al., 2001:5)

Grief and bereavement can be seen as individual states, whereas mourning is culturally shaped and socially prescribed. **Grief** is an individual emotion/ set of emotions, cognitive and behavioural responses. **Mourning** is the external behaviour and **bereavement** is the state of being. Leader reflects on the terms **mourning** and **melancholia** (the title of Freud's 1917 essay). "In mourning, we grieve the dead, in melancholia, we die with them" (2008:8).

Assessing Grief responses

In this section, I examine the manifestations of grief, explore other terminologies currently in usage in grief literature and discuss the validity of bereavement risk assessment.

Grief is a normal and natural reaction to loss and change. The meaning of the loss or change to an individual is critical in determining the nature of any grief response (Quinn, 2005; Neimeyer, 2006). Bereavement and loss are not discrete events; they occur in, emerge from and interact with the nexus of social, relational and cultural norms and from life experience.

There may be widespread physical and emotional reactions. Grief researchers (see for instance Doka, 1993; Rando, 1991; Stroebe and Schut, 1999; Worden, 1991) and practitioners evidence cognitive, physical, emotional and behavioural elements to the manifestations of grief. Put simply, grief is experienced in the body, the mind and in the social media. The following summaries categorise what are universally acknowledged as 'normal' grief reactions.

Physical experiences: can include lack of energy, lethargy, tightness or hollowness in the stomach, chest, throat, muscle weakness, nausea, dry mouth and a sense of shortness of breath.

Emotional experiences: can include a range of reactions such as a sense of shock, numbness, disbelief; anger, anxiety, guilt, helplessness, and profound sense of sadness. Relief felt by bereaved people may still be regarded as a primary emotion, leading to a secondary sense of guilt.

Cognitive experiences: can include impaired memory, concentration, sense of purpose and reduced intellectual acuity, confusion, preoccupation with thoughts of the person who has died and sensory or hallucinatory awareness of the deceased.

Behavioural experiences: can include appetite and sleep disturbances, social withdrawal or the antithesis of frenetic, restless activity, absent-mindedness, crying and sighing and a sense of being 'lost'.

Although palliative care and bereavement education is a growing national and international field of practice, the academic and research community remains relatively small. This fosters collaboration with and awareness of published material in the Americas, Europe, and Asia-Pacific region. In differing cultural backgrounds I have perceived variations in the construct of grief. Theorists from the United Kingdom appear less pathologising and

have a greater recognition that the variances of grief sit within cultural and social explanations and norms. North American constructs of grief places greater emphasis on symptomology. Prolonged, complicated or pathological grief are terms utilised to describe the great variance, duration and severity of grief reactions perceived as outside 'normal' ranges. Contemporary literature e.g. Prigerson, 2008, cites use of the term prolonged grief disorder to refer to the bereavement specific syndrome, a pathological form of bereavement related psychic distress. Previous terms such as complicated grief (abandoned due to lack of clarity), traumatic grief (superseded because of the resultant confusion with post traumatic stress disorder), and pathological grief (perceive as pejorative) illustrate the changing face of bereavement theory, terminology and research. Whether the variances in grief expression are associated with pathology and warrant inclusion in the Diagnostic and Statistical Manual of the American Psychiatric Association, 1994 (known as the DSM IV) has recently been advocated (Prigerson, 2008) remains contested. The recognition that grief may be acutely distressing and functionally impairing are cited as reasons for inclusion within major depressive disorders. Grief, however, currently sits outside the DSM IV scope, thus outside funding for interventions.

The term "disenfranchised grief", used by Doka (1993) refers to a grief that cannot be socially sanctioned, openly acknowledged or publicly mourned, leading to difficulties in bereavement. Disenfranchised grief arises where the death is either stigmatised or hidden. Some examples are the death of a same sex, extra marital or ex partner, or non-bereavement grief in instances where an ill person is physically present but psychologically absent. Corr (in Reith and Payne, 2009) elaborates a more complex understanding of disenfranchised grief: disenfranchised relationships, where the relationship with the deceased person was not recognised, disenfranchised losses, where the loss is not recognised socially as a loss, such as a non-death loss of the persona or physicality of

a terminally ill person. Disenfranchised deaths are stigmatised deaths which, in some instances, may not be openly discussed. These include deaths from suicide, familial homicide and previously included death from diseases such as AIDS. It is my contention, that there is an emerging construct of disenfranchised deaths, related to tobacco, alcohol and recreational drug usage.

The assessment of bereavement risk remains the domain of the psych-social team members in a palliative care setting. This assessment may be guided by a specific tool, such as Parkes bereavement risk assessment index as noted in Reith and Payne, (2009: 137). Serious complications in a minority of bereaved people strengthen the argument for the use of a bereavement risk assessment tool. As noted in Reith and Payne (2009) most bereaved people describe themselves as feeling as they would have expected, given the circumstances. However, most bereaved people who are depressed see themselves as being different. While some indicators assist assessment, acceptable levels of reliability, validity and the contested time when such an assessment is administered remains open to debate (see Payne and Rolls, 2009; Reith and Payne, 2009). The United Kingdom National Institute for Clinical Excellence concludes that "Individual clinical judgement is currently the most effective way of identifying those at risk, as risk assessment cannot be relied upon as a predictor of outcome" (NICE 2004, para 2.53 in Reith and Payne 2009). The multi-faceted social work assessment would include investigation of the nature of the relationship, previous experiences of crisis or loss and how they have been managed, the time and manner of the death, concurrent stressors and social networks available to the bereaved. Further discussion on the transition from caregiving to bereavement, including indicators for complex bereavement is examined in greater detail in chapter six.

Overview

In this chapter I have reviewed contemporary bereavement literature and tracked the progression of theories from 1917 to the present. I have also detailed the recognized transforming impact of grief on an individual's cognitive, behavioural, emotional and physical state. The chapter has provided the essential backdrop to the wider context of this thesis that is, caregiving and bereavement. I have omitted from this discussion those caregivers, usually parents, who care for a child with a terminal illness. This group of caregivers falls outside the scope of my research. The following chapter covers the methodology underpinning this current study including the rationale for employing a narrative approach and the research process undertaken to examine the experiences of participants during both the caregiving role and in bereavement.

CHAPTER FOUR

RESEARCH METHODOLOGY AND RESEARCH DESIGN

For a moral agent to cultivate and maintain his ability to see well, he must learn self reflexivity, and be open to healthy self scrutiny (and in many cases to scrutiny from colleagues and patients). He must learn to recognise and consider sources of his own ignorance, and he must learn how to come to know what he doesn't know.

Christy A. Rentmeester, 2007:59

Methodology and Method

The question that frames this research study is **“In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of grief in bereavement?”**

This study was designed to contribute to a deeper understanding of caregiving within the palliative care context. As the research progressed, it became clear that, rather than finding causal factors between caregiving and bereavement, this paper is an examination of the experience of caregiving for a terminally ill family member and the experience and process of bereavement. This chapter is divided into two sections: section A report is the methodological theory that lies behind this study. Section B is the practice implemented in this research.

Introduction to Chapter

Previous chapters have situated social worker’s awareness of caregiving and bereavement within a palliative care multi-disciplinary team. The purpose of this chapter is to provide an overview of the methodology that has informed this research. This chapter is divided into two sections. In section A narrative theory and phenomenology are discussed and defended as constituting methodological framework suitable for palliative care research, specifically for this study of caregiving and bereavement. In section B of this chapter, I provide an outline of the qualitative research methods including study design, ethical considerations and data collection of the transcripts. This chapter also includes a reflection of the strengths and weaknesses of the chosen research design. The conclusion of the chapter introduces the interview participants to the reader.

Section A Methodology

Reflexivity is essential during the research process. A researcher's implicit values invariably influence their choice of research problems, how research questions are framed, how research is conducted and how findings are interpreted. (Cram, 1997:47)

My choice of research topic is influenced by my employment as a social worker within a hospice service. In this role there are two aspects to my work: support of family caregivers and bereavement follow up. My knowledge of how others talk about their experiences of caregiving and bereavement informs my practice and enables a construct of empathy, the emotion of shared understanding. I am familiar with the language, culture and symbols used by family caregivers through my 13 years experience of working in a palliative care setting. Yet I remain distanced from the constructs of the duty and obligation of being a caregiver and from the conflicting emotions of grief and relief that are the narratives of my client group. Being an 'outsider' I run the risk of objectifying rather than representing the experiences of caregivers (Cram 1997). The tools to assist the representation of stories include reflexivity about personal values and beliefs. Reflexivity is essential within the framework of phenomenology. Throughout this research process clinical, academic and peer supervision have been and remain imperative to my working.

Background to Qualitative Research

In the last decades qualitative research methodologies have gained favour in the human and social sciences. The previously held notions imbedded in quantitative research upheld the ideals of objective 'truth', scientific exactitude, and research objectivity. Qualitative research, on the other hand, attempts to deepen meanings, to discover understandings and new insights that might escape quantitative studies (Rubin and Babbie, 2008).

The increased popularity of this methodological framework was influenced by two factors: the rise of the second wave of feminism from the 1960s and the challenges from within traditional research practices. The women's movement challenged the structures of power in social, political and educational spheres, influenced by a Marxist discourse on issues such as the division of mental and manual labour. In feminist theory, the personal became the political. The second challenge to quantitative research was the questioning of 'absolute' truth in scientific facts and theories. The positivist, empirical research approach was based on the scientific explanations of the European eighteenth century Enlightenment period. It was these assumptions about absolute truth that were challenged. It should also be noted here that contemporary research practice has been heavily influenced by policies requiring service users' involvement in planning for health and social care services. Research conducted with service users ensures that the 'voice' or perspectives of service users are considered in both research and practice.

Reliability

The value of research is dependent on its reliability, trustworthiness, validity and effectiveness. Qualitative research is to illuminate experience or to generate a theory rather than prove a hypothesis. Therefore external validity does not depend on scientific exactitude or being replicated, but on trustworthiness and credibility (Reese et al., in Goodman, 2001). Reliability is defined as the extent to which the set of meanings derived from several different sources is congruent (Franklin and Ballan, 2001). Reliability may in fact be referred to as 'dependability' in qualitative research. The audit trail that demonstrates dependability is four-fold: condensed verbatim accounts of interviews, a log of events at time of interview, an ongoing reflexivity journal and a running record of analysis and interpretation of data (Franklin and Ballan, 2001: 276). The ethical underpinning of this research is dependent on such an audit trail. Reflexivity, professional, peer and academic supervision have enabled

transparency and internal consistency. External and internal reliability may also be demonstrated by explicit details of the philosophical framework used and the clear research design.

Narrative Approach and Phenomenology

A qualitative study was conducted to inquire into the experience of family caregiving and of reflections of that identity in bereavement. This is a descriptive study using phenomenology to portray the experience of caregiving and bereavement, as this methodology allows for a profoundly reflective enquiry into human meaning (van Manen, 2002). I chose a phenomenological inquiry to guide the research, because it allows for exploration and investigation of the complexities within the social world. Social workers are concerned with the social world. The phenomenological approach to understand the social world places importance on the every day activities in which people engage and the meanings invested in those activities. Human science aims at explicating the meaning of human phenomena and at understanding the lived structures of meanings such as phenomenological studies of the lifeworld (van Manen, 1990: 4). This study explored the experience of being a caregiver for a terminally ill family member and the experience of subsequent grief in bereavement. My interest lay in hearing the accounts of the participants and the ways they make meaning from their experiences. Narrative does indeed assist in making sense of experience, allows reflection on a phenomenon and enables action within lives (Squire, Andrews and Tambouku, 2008). "Researchers who are interested in narratives as individualised accounts of experience tend to be the most convinced of the significance of stories as a way of expressing and building personal identity" (ibid. :6). In the context of terminal illness this search for meaning, identity and sense of being human is an appropriate match with this research. Narrative is employed in order to understand how personal lives transcend change (ibid.).

Phenomenology research methodology is a search for what it means to be human (van Manen, 1990). The methodology employed focuses on the lived experience and allows for collection of rich data through apparent "conversation". Like the tools of my social work practice, the techniques used may appear superficially like ordinary social intercourse but unlike ordinary conversations there is a technique in orchestrating or conducting such apparent social interaction. Phenomenology requires a strong theoretical framework to dig below the surface, to describe what the experience feels like and to allow the creation of a narrative both rich and interpretive (O'Leary, 2005). The knowledge of the theoretical framework is what differentiates phenomenological researchers from being "only" story tellers (Pawson, 1999). The intent is for the researcher to "come as close as you can to understand the experiences being lived by the participant as they do" (Daniels, 2005). The intention as researcher is to be fully present in the re-telling of the lived experience of the research participant as s/he reflects on their past experience.

What we hear from [clients] is not simply an account of an inner world of feeling and meaning-making but a narrative which reveals the structured way of telling the 'story' of experience reflecting a historically and culturally specific perspective. (Machin, 2005: 39)

A phenomenological approach has the potential to contribute to knowledge accumulation in palliative care, especially the little researched arena of caregiving and bereavement identity. Participants themselves are expert in their own experiences, people tell their own story in their own terms. Part of the method is to uncover the layers of meaning. The literature endorses the following features in a phenomenological approach:

- (1) It presents dense descriptions of participants' experiences and the way they make meaning from those experiences. This includes analysis of both data and language.
- (2) It provides reliance on the actual words of the participants.
- (3) Excerpts and themes are used to develop an exhaustive description of the participants' experiences.
- (4) The data analysis takes place as the researcher scrutinises and re-reads the material so as to reveal the structure and the meaning configuration. The researcher becomes "immersed in the data" (Cohen, 2001).
- (5) The material is clustered by topic to reveal meaning and how this meaning is created. The emphasis is on commonality that is present in the diverse appearances of the phenomenon.
- (6) Studies using phenomenology is particularly useful where there is little research being undertaken in a particular field.
- (7) Participants are selected on the basis of their first hand experience of the phenomenon and for their capacity to render descriptions of that experience. (Cohen, 2001; O'Leary, 2005; Moerer-Urdhal and Creswell, 2004; van Manen, 2000).

Qualitative interviewing allows the researcher to explore open ended questions without limiting participants to a fixed set of answers. This encourages self disclosure and the opportunity to reveal multiple layers. In order to effectively explore participants' narratives of their own experience, the method needs to allow for in-depth probing of their thoughts, experiences and perceptions. Interviewing allows the researcher to begin to understand another's perspective and to learn things not observable by other means. The style of the interviews and other research design are the focus of the next section.

Section B Research Methods

The question that frames this research study is **“In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of grief in bereavement?”**

This study was designed to contribute to a deeper understanding of caregiving within the context of terminal illness. I was interested in the experience of the phenomena of caregiving and subsequent bereavement. The research question that frames this study shifted during the progress of the research. Rather than seeking causal factors, this study is an examination of the experience of caregiving for a terminally ill family member and the experience and process of subsequent bereavement. In order to gain insight into the reason why people make decisions about caregiving it was necessary to conduct a qualitative investigation. In doing so, this study attempts to reduce the gap in research on caregiving, in that it queries participants about their own experience. The best way to uncover the reason and motivation for family caregivers is to ask them. Selecting an appropriate research strategy is key to ensuring that the research question is addressed in a way that has value and is congruent with the overall topic, questions and purpose of the research. This study sought participants who were caring for a terminally ill family member and who were willing to be interviewed.

Interviewing

The purpose of this study was to hear the voices of caregivers. This precluded research data collection methods other than interviews or questionnaires. I examined a variety of research literature on the process of interview designs (Rubin and Babbie, 2008; Thyer, 2001). The literature review indicated three specific face to face interview designs: structured, semi-structured and unstructured. Structured interviews require the ‘script’ to be read verbatim, with no variation in the text and are governed by a

rigid procedure. This may come at the cost of neglecting the depth and complexity of participants' experiences. The antithesis, unstructured interviews allow a fluid interaction between the researcher and participant, and are completely open-ended. The participant determines the direction that the discussion takes. As my goal was to specifically unearth information on caregiving, I required some structure. Goodman (2001) also notes that establishing pre-existing categories in an interview structure reduces the risk of human error. In the light of the literature, I chose to use face to face semi-structured interviews. During the interviews participants were able to canvass any topic that they felt was relevant to them, but a topic guide ensured that all necessary topics were covered as much as possible (see Appendices 4 and 5). Because of the subjective nature of the interviews and the emotional content of the topic in general, value was placed on allowing the participants to take the time that they needed in discussion. I remained aware that these interviews were not therapeutic or psychotherapeutic interventions. The interviews allowed expression of deep interest first in the caregiving being undertaken, to demonstrate validation and appreciation of the essential nature of home caregiving in the palliative care context, and second in the grief experience.

As a qualitative research undertaking, the purpose was not to validate a theory or to present a hypothesis. As researcher, I did not have a preconceived theory. I was and remain deeply interested in the meaning family caregivers attribute to their role. The second aspect of the research study is around the identity that those same caregivers forge for themselves in bereavement. Support of family members during the terminal illness and bereavement are two aspects of my work as a palliative care social worker. These two threads guided the aims of this research. The specific aims of the project were:

- (1) To explore with participants their experience of caregiving and any meaning they take from this role

- (2) To determine what factors influence caregiving being undertaken by which family member
- (3) To explore whether any aspect of the role of caregiver assists in the new role of bereaved person
- (4) To explore what it is that sustains the caregiver in providing care for a dying person
- (5) To explore the meaning that bereaved people make of the loss in bereavement, having been a caregiver.

Study population

The target population for this multi-site study was informal family caregivers of terminally ill people in the Mary Potter Hospice Service. This hospice serves the greater Wellington area (excluding the Hutt Valley), with three community teams and one 18 bed in patient unit. An eligibility criterion to the hospice service is a diagnosable terminal illness with a prognosis of approximately twelve months or less. Identification of potential study participants was carried out by specific members of the multi disciplinary teams of Mary Potter Hospice service, excluding the team that the researcher works in. Each participant was interviewed on two occasions: the first when they were undertaking a caregiving role, the second when their caregiving role had ceased due to the death of the person. All participants were caring for a terminally ill family member at the time of first interview. All participants 'opted in', as opposed to 'opting out', that is, all were entirely self selecting. As with small qualitative studies the participants were not necessarily seen as representative of the hospice client group carers. The small sample precludes this verification. Competence in speaking and understanding English was determined. No clinical records were referred to, in that I did not use my position as a social worker for the organisation to access patient notes.

Participant selection method

The recruitment procedure was set up to be as simple as possible for team members. It was important for the researcher to negotiate access to potential participants from clinicians. The clinical multi-disciplinary team members were asked by the researcher to hand out the 'Research Participant Information Sheet' (Appendix 3) to any family member who met the caregiving and English language criteria. This follows palliative care research recommendations that grief researchers should initially contact participants by letter, provide written information on the project and provide choice (Dyregrov cited in Agnew and Duffy, 2009). The rapidly changing nature of someone with a terminal illness constituted another ethical issue. Timeliness of recruitment, including sensitivity to the stage of the illness where it would not be inappropriate to request participation from the caregivers was dependent on the multi-disciplinary team discussion and clinical assessment by those team members. Any potential participants then made contact with the researcher directly. In this way participants 'opted in'. This is in accordance with Franklin and Ballan (2001: 276) "All data provided voluntarily might be more consistent across accounts than data collected from individuals whose participation was mandatory". Information of participant's name, address, contact details and relationship to the terminally ill person was volunteered by the participant at the initial phone contact or at the first interview. The purpose of the research was to overlay the experience of bereavement on the caregiving experience. Therefore both interviews in sequence were required. On several occasions potential participants made contact and wished to participate in the research interviews, but the terminally ill person died before the caregiving interview was completed. I chose not to conduct the bereavement interview with anyone who had not participated in the caregiving interview. The same written information (Appendix 3) was offered again to each participant at each of the two interviews.

Purposive sampling method was adopted as the most appropriate to gain participants for the study, rather than random selection. Participants selected by purposive sampling, are exemplars and enable the researcher to collect rich data, from which most can be learned. (Franklin and Ballan, 2001)

Recruitment of participants

For the purposes of this research project, it would have been unethical to request research participation from a client group with whom I have an existing relationship. Because of the potential for indebtedness I retained one degree of separation from the recruitment process to avoid participation due to obligation. This meant that the initial information sheet was distributed by a third party. Gaining access to potential participants via a third party is common practice to avoid coercion (Appleton 2004). However, this makes the researcher dependent on others for recruitment. This process did not serve me well in terms of numbers, in that I was not able to defend the undertaking of research and thus perhaps increase potential participants. However, transparency was achieved. McNaught (2002) when recruiting for participants in a hospice service refers to some patients and families responding to research participation out of duty, or because an authority figure (the doctor) had suggested it.

Ethical considerations

This study was granted ethical approval from the Health and Disability Ethics Committee (Central Ethics Committee) Wellington in June 2008 (Appendix 9). An amendment was granted in November 2008 to extend the locality to include the Kapiti locality (Appendix 10). I chose to present myself to the Ethics Committee hearing to defend the place of research in palliative care and to answer any questions that arose from the committee members. It was noted in a letter granting approval that the committee wished to commend me on the intention to give a bound copy of the

participant's own transcript at the conclusion of the study. As the field of research was covered by the Health and Disability Ethics Committee, and a memorandum of understanding exists between the two committees, I did not need to request approval from the Massey University Human Ethics Committee. Endorsement was given by the medical director of Mary Potter Hospice and the Māori Liaison also employed by the hospice (see Appendices 1 and 2). I was also guided by the Aotearoa New Zealand Association of Social Workers Code of Ethics (2008). Appleton's discussion on ethics approval is underpinned by the notion that beneficence indicates that participants will be "untouched or unchanged by the experience" (2004:260-261) rather than being mindful of the ethical challenges involved.

All participants completed and signed an informed consent form prior to each of the two interviews (Appendix 7). Informed consent focuses on two main areas. Firstly 'informed' implies that all potential participants receive sufficient information about the study, in a suitable language and format so that participants fully understand the implications of what they were agreeing to. Secondly, 'consent' implies free and voluntary participation without coercion. Participants were given full information and opportunity for questions. All respondents also were aware they could withdraw at any time. Participation or non participation in this research study was explicitly stated as being unrelated to receipt of hospice services.

All transcriptions of the interviews were undertaken by a single transcriber, who signed a confidentiality agreement prior to receiving any audio recordings.

To ensure confidentiality of the participants, pseudonyms were discussed with each individual at the time of the first interview. Some participants chose their own pseudonym. Names of others mentioned in the interviews are referred to by a random letter only.

The researcher is unconditionally responsible for the integrity of the research process. My role as a researcher and as a social worker is guided by a code of ethics to which I am required to adhere. I work for the organization that the participants receive services from. It would be unethical to request research participation from a client group with whom I have an existing or future therapeutic relationship. The participants are from the two geographical teams that I do not work in. During the research process, high consideration was given regarding ethical decision making. For example, the method of recruiting participants was separated from my direct sphere of influence.

As noted, professional, academic and peer supervision has continued to guide this research process. By these steps as well as reflexivity and journal writing to record my own processes I have endeavoured to remain open to the research inquiry rather than pre-empting any research outcomes.

Finally the ethics of conducting research within the palliative care context has received considerable debate and discussion. As a researcher, I have remained fully engaged with the debate. This will be further addressed in the final chapter of this thesis.

Data Collection Methods

I adopted two semi-structured interview schedules, (Appendices 4 and 5), which allowed for an interview protocol so that the same questions would be asked of all participants in a similar order. This method was felt to be the most appropriate method for generating information, insights and reflections with the intended participants. The use of interviews proved to be compatible with the tenor of the research, by allowing some direction, but retaining an element of interactive dynamism, spontaneity and flexibility. The first interview was to take place during the period of caregiving; the second in the period of bereavement. Conducting a

qualitative research study over a period of time and interviewing participants more than once ensures that the research data is not based on a single snap-shot in time (Rose, 1998). The interview question design enabled exploration of meaning, and interpretations that people themselves attribute to that meaning. The questions were relevant to the research aims yet allowed enough scope for the participant to accentuate areas which were important to them or that surfaced for them at that time. It was also helpful to have a mixture of 'factual' and 'feeling' questions, to allow for participants to retain a sense of equilibrium. I did not conduct a pilot study, but did familiarize myself with the six or seven questions.

I now wish to discuss both the advantages and disadvantages of interview methods. People often need to tell their stories in order to communicate meaning (Hera, 1995; Neimeyer, 2006; Patterson, 2008). It is argued by Bruner in Patterson (2008) that all humans have an inborn tendency to tell and understand stories. Maitland explores this in some depth

One of the definitions of identity or selfhood being explored at present in both philosophy and psychiatry is the idea that the ability to construct a coherent narrative of one's own life circumscribes identity - to be an individual is to own a narrative self. (Maitland, 2008:240)

The process of telling gives voice (literal and metaphorical) to the lived experience and assumes that the participants have a vital source of information (Goodman, 2001). This is something other qualitative researchers have noted. Interviewing is one of the most powerful tools in qualitative research and is certainly the most used one (Goodman, 2001). An experience centred narrative approach assumes that narratives are sequential and meaningful; that they represent experiences, thus reconstituting as well as expressing that experience (Patterson, 2008). Face to face interviewing allows opportunity to observe non-verbal cues

and to develop a wider picture. This is especially true when the participant is interviewed in their own home environment. Interviews result in a high response rate to research questions once people are recruited. Planned interviews allow for preparation and reflection, something I built into the time consideration.

Disadvantages include lack of guaranteed anonymity for participants and researcher bias, both threats to the validity of the research. This is especially true when the researcher is the sole person carrying out the study. Narratives cannot be replicated exactly at another occasion (Patterson, 2008). Interviewing is expensive in time and resourcing. Recording, transcription, travel costs, and the risk of emotional depletion due to prolonged face to face contact are all noted by Goodman. The interview skills required for social work research differ from those required for social work practice (Goodman, 2001). My awareness of being an experienced practitioner and a novice researcher formed part of my reflection and supervision. I return to my own reflective accounts of my role as researcher in greater depth in my final chapter.

Interview process

In the first instance, participants contacted me by phone. Of the four participants recruited, two people left messages on my answer-phone, two spoke with me directly. The answer phone-messages were transcribed. This began the storytelling process for both participant and researcher and this was when I first began hearing their narratives. Interview times and place were arranged, usually two to three days following contact. On one or two occasions I contacted the participants again on the interview day to reconfirm. This was due to two factors. The rapidly changing nature of palliative care patients make planning ahead problematic. Secondly, one known characteristic of grief is that information is forgotten.

Each person took part in two interviews. At time of writing, one participant was still caregiving; the bereavement interview has not taken place. It is my intent to conduct the bereavement interview with this one participant in the future, in full awareness that the data from this interview will not be included in this thesis, due to time constraints. All interviews were prepared for in advance, allowing up to one and a half hours for each interview. Each interview took place during my own time, in the participant's home or at the hospice building in Wellington - whichever was their preference. I was aware of the sensitive and personal nature of the interview material and the potential for participants to express distress. I ensured adequate safeguards: thesis supervisors contact details were given in a written format. Because I am undertaking this study as an extramural student, the academic staff supervising this thesis are not based in Wellington. To avoid participants incurring long-distance call costs, the contact numbers were all Wellington numbers. All participants were again made aware of the facility to access counselling or social work support from the appropriate team member should they wish to do so. No late afternoon or evening interviews were scheduled, intentionally, when participants would have been left to face the evening alone. At the interview each participant was again offered an information sheet at each of the two interviews. Before recording, I showed each participant the consent form allowing time for any questions prior to signing. No one declined taping or consent. The other matter discussed at this time was whether they wanted a bound copy of their own transcript. Three of the four participants expressed appreciation at this. It is my intention to speak with each participant prior to posting the transcripts to ensure adequate psychological preparation for each individual. This practice stems from my experience: I would not send such poignant and emotionally raw material by post to these women if they were not expecting it.

I also obtained contact details, ages, relationship to the ill person and their medical diagnosis. One participant had moved city to undertake the

caregiving role, and anticipated returning follow C's death. In order to arrange a bereavement interview at a later date, it was important to ensure her own contact details were obtained. Each interview was between 45 and 90 minutes.

At the end of each interview I wrote field notes of my observations, thoughts and reflections. These plus other notes (answer phone message transcriptions, notes from initial contact, the choice of pseudonym) were added to the participant's narrative. I also recorded my own reflections including my responses to the sometimes powerful accounts. The reflexive process is essential in qualitative research, especially when the narratives are around loss and grief (Neimeyer, 2008 a).

All tapes were transcribed by an employed person. I am aware that the close attention to the narrative during transcribing is beneficial in analysis, that is, the attention to the voice, responses, emphasis on phrasing, and pauses of the participants all lead to an intimacy with the data. The process of turning audio records into written records is lengthy to an inexperienced person. As I am not a full time student, I did not have the time to transcribe the tapes myself. In case of technical difficulties I chose to use two different recording machines at all (but the initial) interviews.

Data Analysis

In order to organize and interpret the data I followed a structure for empirical phenomenological research analysis. Arie Cohen (2001) describes the steps in this approach as follows:

- (1) Immersion in the data which requires reading and re-reading the transcripts many times. This is a mindful exercise, requiring reflective attentiveness. As the interviews were on audio recordings, another approach is listening repeatedly.

- (2) Statements that describe or are relevant to the phenomenon are identified and clustered into themes.
- (3) These excerpts and themes are used to develop an exhaustive description of the participant's experience.

Data analysis must allow for the description of what the experience is without being mediated or obstructed by preconceptions. In order to organize and interpret the data I employed procedures that were adopted from phenomenology described by van Manen (2002). The initial step in beginning such an inquiry is 'bracketing' - suspending or setting aside biases, everyday understandings, theories and judgments. This is in order to focus on the meaning conveyed by the participants. This practice of 'bracketing' is akin to the social work concept adopted by skilled professionals, of being non-judgmental or suspending disbelief. Unlike grounded theory research, where the literature search is subsequent to data collection, I began this study by immersing myself in caregiving and bereavement literature. In order to 'come afresh' to the participants, bracketing was a conscious process prior to each interview. This I found was parallel to some aspects of my client based social work, where my knowledge of grief theory is "put aside" as clients describe often very raw experiences of grief. At these times I am compelled to be 'in the present' with the experience of grief. The practice of being in the moment was undertaken at each interview. This process of mindful bracketing enabled me to focus on the described essence of the experience during the interviews.

Coding was used to analyze the interview transcripts. The meaning conveyed by the participants was clustered together thematically. The process for achieving this is immersion in the data "reading, re-reading and re-reading" (Cohen, 2001). Comparative analysis was then used to group the coded data into themes. These themes represent the common experience of the four participants as they reported their experience of

caregiving and 3 participants as they reported their experience of bereavement. There are various ways in which phenomenological writers may structure their texts and this study report is structured around the existential lifeworld themes of **lived body** (corporeality); the **lived other** (relationality); **time** (temporality) and **space** (spatiality). 'Lifeworld' simply refers to 'our lived world' (van Manen, 1990: 105). The lived body refers to 'the phenomenological fact that we are always bodily in the world' (ibid: 103). The lived other is the 'lived relation we maintain with others in the interpersonal space that we share with them' (ibid: 104). Time is subjective time as opposed to clock or objective time' (ibid: 104). Finally space is 'felt space', the space in which we find ourselves affects the way we feel (ibid: 102). In line with phenomenological qualitative research, findings are presented using these four overarching lifeworld themes in the content analysis.

The confluence of the four themes as cited by van Manen and my utilisation of these themes shall now be discussed. The themes articulated by the participants and those articulated by van Manen were arresting in their synthesis. The significance of spatiality and its influence on the expression of grief has been on the margins of my thinking for a number of years. This idea presented itself as I reflected on the depth of the narratives clients spoke, and where these conversations occurred. The physical environment and the degree of privacy seemed to influence what was revealed. As I have become aware of this in my social work practice, I have intentionally created a space where disclosure was encouraged. Van Manen's use of spatiality as a life world theme therefore had a ready reception in my thinking. This was deepened by my reading of Exley and Allen's 2007 article which explored the meaning of home as a site for caregiving. My interest in the concept of time was informed by working in a palliative care setting, where 'time' is limited for the terminally ill person. This was furthered for me as caregivers did not only speak about the preciousness of remaining time, but also the suspension and unreality of

time, and the disruption of time. The data, in its raw narrative, is primarily about impending death or about bereavement. As phenomenology is primarily about existential issues it is perhaps not surprising that that van Manen's four life world themes made such powerful impression on me. I encountered his writings at a time I was attentive and ready to respond to what presented itself, having discounted other analysis methods as alien to the data I had. As I read and re-read the experiences of the interviewees, the convergence of my reading of van Manen and the transcripts came together. I was then able to look at the transcripts more closely and notice the references to space, time, relationships and the body.

Strengths and weaknesses

At the conclusion of the recruitment period, there were fewer participants than anticipated. It was also difficult to find men for the study. All participants were women. Other researchers on caregiving (Ross, 2008) also comment that the majority of caregivers tend to be women. The method undertaken to recruit caregivers, as per the study design, has several disadvantages. The researcher was dependent on others within a multi disciplinary team to firstly identify potential participants and to give out give the information sheets. Initial discussion with that team advocated that all family members who met the criteria for this study be given an information sheet. Team members acknowledged that this did not happen. Other than regular discussion (in meetings, phone and by e-mail), there was little that the researcher could do to increase the number of respondents. The reasons for the small number of respondents can only be surmised. They may include the rapidly changing nature of terminal illness, the time and focus constraints of the team members, possible screening undertaken by team members for potentially eligible participants and the priority relegated to research by team members. Caregivers themselves may have not pursued participation if they themselves saw their role as unremarkable. One phenomenological study noted that it was not that

people were unwilling to participate, but that 'they felt they had nothing to tell me' (Bland, 1999:51). The changing territory of those with terminal illness and those who care for them may also have impacted upon recruitment. These issues in themselves are outside the scope and time constraints of this particular study. The interviews that were undertaken yielded some profound narratives of resilience and meaning making for caregivers as they struggled to re-shape their identity. It is acknowledged that this is a small study undertaken in a palliative care service in the Wellington region, New Zealand and it may therefore be difficult to generalise the findings. Participants indicated they had been given an opportunity to make a valuable contribution in the realm of palliative care. Through participation they were empowered to 'tell their story' validating their own experience as caregivers.

Chapter summary

This chapter outlines the research process concerning the role of caregiving for a terminally ill family member and the experience of bereavement. It provides a description of the methodological framework, study design, and analytic strategy for the investigation of the ways in which the experience of caring for a terminally ill family member has on the experience of bereavement of these four participants. The study was conducted in two interviews with each of the participants. The first while caregiving was ongoing, the second when caregiving was over. Data obtained in each of the caregiving and bereavement interviews was transcribed. The various themes as relayed by the caregiver were used to develop the four thematic structures in order to enquire deeply into the research question. The following chapter introduces the data and categories constructed in which to interpret the interview data. Both the caregiving interviews and the interviews conducted during bereavement are analyzed together.

Profile of the Participants

The interviews were conducted between September 2008 and February 2009. I had allowed a greater time frame (July 2008 to May 2009), but recruitment was problematic. Several other potential participants contacted me, but by the time of interview (usually three to four days after contact) they no longer met the eligibility criteria.

In this section, I introduce the research participants and include a table as a diagrammatic representation of the four participants who completed interviews. Despite the small sample, there were voices of diversity, two New Zealand Pākeha, one New Zealand Māori and one who identified as other European. This ethnic mix is in keeping with the patient population of the hospice. Men were not represented which may be a bias of the purposively selected sample.

“Jennifer” identifies as New Zealand Māori as did her husband for whom she cared. The initial contact was an answer phone message, where she identified herself and her contact details, and *“that K from the hospice gave me an information sheet ... and, um ... I thought well ... um ... I ... I might be able to help you...[pause] ...or I might not. Um ... my husband is probably in the last few days ... ah at the stage he is. But my phone number is----- and we’ll see [laugh]- what sort of space I am in. Thank you. Bye”*. She is in her late 40s, early 50s. The initial interview was conducted in their house. There were many family and friends evident when we met for the early afternoon interview. The house and outside area was modified to accommodate extra people, with a marquee housing a BBQ and eating area. This was reminiscent of *marae* the Māori cluster of communal buildings. “Jennifer” was very engaging, and a feature of both interviews is the long pauses as she reflects before speaking.

“Catriona” identifies as New Zealand Pākeha as did her sister for whom she cared. Catriona moved city for several months *“leaving behind my home*

and my husband' and shared the caregiving role with her sister's friend. When I met with her, they had established a strong routine of who was 'on duty' and when. Catriona lived in her sister's house with her. A friend would arrive at mid-day, enabling Catriona to "have the afternoon off". Catriona also left a message on my phone, so the first contact I had was a clear concise message "Hello, my name is-----[first name only] and I'm ringing because the information about your research project, Virginia, was given to me by the hospice people. I'm living with my sister who is terminally ill at the moment and I would be interested in taking part in your survey, if I would be suitable. My number here is-----, and that's my sister's phone number, but I am here most of the time. I'm looking forward to hearing from you. Thank you". She is in her late 50s, early 60s, some 7 years younger than her sister. The initial interview was conducted at the hospice in a private room with a 'do not disturb' sign on the door. Catriona set the time for early afternoon when she knew that she could leave the house. Catriona was very articulate and a feature of both interviews is her clear use of language. She stated that she appreciated the opportunity to participate and that she was "fascinated and impressed with the fact that people are doing research like this and taking the role of the hospice so seriously and wanting to get it right".

"Mavis" identifies as New Zealander. She cared for her husband. She is in her mid to late 70s as was her husband. The initial contact was a phone conversation, when an afternoon interview time was set up at their home "when he would be having a rest". On that day, I received a call from the hospice staff, asking to postpone as "things were changing". I later made contact again with Mavis when "Mike" was in the inpatient unit 3 days later. She said she still wanted to participate, and was interviewed 10 minutes later in a private room at the hospice with a 'do not disturb' sign on the door. Family were with Mike so she said that she "could leave him for a while".

I contacted "Barbara" at the request of hospice staff, who said she was keen to participate. She was very keen and *"hoped [her] story would be helpful"*. She is an 84 year old immigrant from Europe who cared for her husband who is the same nationality as her. She wanted pseudonyms that would not reflect their heritage. We arranged a morning interview *"I'm up early"* at a time when her husband was in the hospice for respite care. I went to her home. At time of writing, Barbara is still undertaking the caregiving role for her husband. Given the time constraints for this thesis and the uncertainty of his illness trajectory I shall not use data from a second interview with Barbara for this thesis.

TABLE OF PARTICIPANTS

Pseudonym for cover	Ethnicity	Age	Term III Person	Relationship to carer	Age	Diagnosis
"Jennifer"	NZ Maori	Late 40s early 50s	"Jimmy"	Husband	Late 40s early 50s	Stomach cancer with secondaries
"Catriona"	NZ Pakeha	Late 50s early 60s	"Clare"	Sister	Late 60s	Uterine cancer with secondaries
"Mavis"	NZ Pakeha	Mid to late 70s	"Mike"	Husband	Mid to late 70s	Liver cancer with secondaries Previous diagnosis of bowel cancer
"Barbara"	European	Early 80s	"Bob"	Husband	Early 80s	Liver cancer

This table does not indicate the caregiving time period. As discussed earlier, for family members the caregiving role may evolve and is often seen initially in the context of the relationship.

CHAPTER FIVE

DATA PRESENTATION AND ANALYSIS

You pass through the needle's eye

cross the black river

in silence

**C K Stead,
Elegy, 2006**

Data Presentation and Analysis

Introduction

There are various ways in which phenomenological writers may structure their texts (van Manen, 1990). Phenomenology aims at a deeper understanding of the nature or meaning of the everyday lived experience, the systematic attempt to uncover the meaning structures of that lived experience. Phenomenology engages in the analysis of themes which occur frequently in the data. That the engagement of phenomenological methodology as the method framing data analysis for this study has already been explored in Chapter four. The aural nature of story-telling is different from the written word (Burke, 2008); spoken English and written English have a different vocabulary. They generate different genres of literature (Maitland, 2008). Therefore, the interviews for this study were recorded, and then transcribed verbatim. This chapter is based on attending to peoples' spoken accounts. Each transcript was then subjected to continuous reading and re-reading in order to elicit themes and issues that were relevant to family caregivers. This chapter aims at drawing out and analysing those themes. Use of the four existential lifeworld themes as articulated in van Manen has guided the presentation and analysis of the collected data for this study. These themes are corporeality, relationality, temporality, and spatiality. This chapter discusses what participants actually told me, although analysis is my interpretation, it is grounded in their experience. The four divisions are a way of marshalling the data into the four lifeworld themes, and are, to some extent an artificial construct into the categories for phenomenological research. In reality, the four themes cannot be separated from each other. They form what van Manen describes as "an intricate unity which we call the lifeworld - our lived world" (1990:105). The four themes are summarised below. The chapter is then divided into these themes to present, analyse and discuss the data.

Lived body - corporeality: refers to the fact that we always live bodily in the world (ibid: 103). This theme is illustrated by the descriptions of caregiver's experience of the work undertaken; constructs of both burden and privilege.

Lived relationships - relationality: is the lived human relation we maintain with others (ibid: 101). This theme reveals the alterations in family relationships, the transition to bereavement as well as the lived relationships that are established, maintained and negotiated with health professionals.

Lived time - temporality: is the subjective time as opposed to chronological or objective time (ibid: 104) and is of particular significance when caregivers and the terminally ill person have limited time together. The demands made of caregivers are time consuming: however, the caregiver's perceptions relating to time are more complex than being either 'limited' or 'disrupted'.

Lived space/place - spatiality: is the felt space, the space we are in (ibid: 102). Palliative care is provided to people wherever they are. Therefore the use of the term 'home' is as a concept as well as a physical place, denoting expectations of emotional, social and physical security and comfort (Hera, 1995). The geographical language used indicates that some of the caregivers construct their lifeworld in terms of place.

I have interwoven the data from both the caregiving and the bereavement interviews in this one chapter. I have at all times attempted to be true to the words, phrases and speaking styles of the interviewees, to preserve the essence of their experience. It is always difficult to untangle any one influence on a person's life. Different factors interact with each other, distinguishing them can be difficult. I have simply relied on what the caregivers told me. Where their words are taken from the transcripts, I

have employed the usual technique of presenting these words in italics. Each vignette is used for illustration. Family caregiver pseudonyms are employed in all but a few instances. Where they are withheld it is because the risk of identification is obvious. Despite the emphasis on the shared experience of caregiving, the voices of the women themselves illustrate difference, a diversity of experience and perspective. The participants' experience and their search for meaning when their assumptive world is disrupted remain an underlying concept expressed by the participants. On some issues covered by participants, I did not ask specific questions to seek the caregivers' views (see Appendices 4 and 5). Instead I analysed comments in response to the semi-structured interview questions.

Section 1 Corporeality - the lived body

Introduction to concept

In this section the experience of caregiving for a terminally ill family member and the subsequent bereavement is examined from the first existential lifeworld theme - the lived body. Van Manen describes the lived body as "referring to the phenomenological fact that we are always bodily in the world" (1990:103). Caregiving is evidenced as having both emotional and physical impacts on carers (Cantwell-Bartl, 2006), and that carers neglect their own needs in favour of the terminally ill person has been well documented. This chapter therefore engages in discussion concerning both the physicality of caregivers' work and emotional labour undertaken. Grief can also be expressed bodily, as has been articulated in chapter three (p 44). Emotions are corporeal, in that bodily housing is required: one cannot have an emotion without a body; emotion depends on physiology (Murray, 2007, personal communication). This chapter examines the body - corporeality as the lived body of the caregiver in both the physical and emotional. It concludes with a brief discussion on the bodily experiences of grief.

Physical demands

Most academic accounts of those undertaking caregiving emphasise the work involved in providing physical cares: nursing, house-keeping and social monitoring or surveillance of the ill person (Payne, 2004; Payne, 2007). As noted earlier much of the caregiving literature stems from a deficit model, a construct resulting in a burden paradigm. Previous research (Twigg & Atkin, 1994; Thomas, et al., 2002) suggests that illness can disrupt established divisions of labour associated with gender and generation within households. Researchers established that personal care tasks, housework and other care work often have to be reallocated and that the management of a terminally ill person gives rise to 'new' work. The burden construct will view the increased care as an increased demand on the caregiver. The busy-ness of the caregiver is detailed further in this chapter section on time. One research participant in this study, Mavis willingly increased all she could do: the do-ing was easier to manage than the be-ing. For her, this included stocking up the larder with tempting foods, an issue she returns to often in the interviews

Also, I had to constantly ask him 'what do you want to eat?' It was constantly having to [pause] not to think about him but it would be 'what have I got in the cupboards?' ... he would say 'I fancy a bit of fish' so I kept fish in the deep freeze, I still have a deep freeze full of stuff ... I still every now and then turn up something I bought and think 'oh goodness'. I bought some tins of dessert and he thought it was lovely. He went into Mary Potter [the hospice] about two days later so he never got around to eating them

Mavis - bereavement interview

As though preparing for a siege, Mavis ensured her cupboards were full. Death's imminent presence was not talked about between her and her husband, but prepared for as one who prepares for a long winter ahead.

His absence perhaps feels like that winter. Mavis appeared to draw a parallel between her activity and his health: bargaining that if she did more, he would last longer or somehow that by her expending her energy, his energy would not be depleted. Her reflection on this appears 'stream of consciousness' in that the use of tense is not consistent.

I think it's just the thought that he might last that little bit longer ... yeah, the more I do for him is going to make it better. The fact that I take his socks off, which he could probably do himself ... I sort of hover ... thinking that the more I did was going to make things right ... I think that's why I probably do it. Because if I do, he will carry on living

Mavis - caregiving interview

Emotional work

Payne (2007) employs the term 'vicarious suffering', as family members witness symptomatic distress in the terminally ill person. The awareness that caregiving will end on death provides a strong moral imperative for caregivers to provide the best possible care at home. Previous research has described how the provision of this care may come at the expense of the emotional health of the carer. One carer explained

...then I would find myself doing something silly like breaking a glass ... I would never get angry with [the patient] because it was always me doing something silly. I would go into the bedroom and swear to myself.

Mavis - caregiving interview

Superficially, this vignette may illustrate nothing more than fatigue induced clumsiness. However, in the context of illness and disease, glasses break; people don't, items are replaceable; relationships are lost. It may be

construed that irritation was felt in the realm of physical objects breaking, but only expressed when she did '*something silly*'. Maitland recounts this as

Now what happens? What always happens when we try to suppress real fears without acknowledging them. The Terror appears somewhere different; it shifts, in language, as language always does, from the material to the abstract, from the present actual to the symbolic. Now the Terror turns up elsewhere. (Maitland, 2008:130)

This action of swearing allowed her to put words to the anger, thus allowing it to subside. Feelings were being managed by displacement. The management of feelings is referred to as emotional work. Emotional labour is the emotional effort made by individuals to manage their own feelings and those of others (Thomas, et al., 2002). The term is derived from the study on airline employees (Hochschild 1983); personal emotion may be suppressed due to a sense of obligation or protection of another. Hochschild's analysis not only includes suppression of emotion, (containment of emotion to avoid distress to another) but also expression of disingenuous emotion for a [commercial] purpose. Management of emotion is a crucial aspect of what informal caregivers do, in order to maintain a sense of control, to assist the terminally ill person retain their sense of identity and to "stave off the nightmares of death, loss and major life change" (Thomas et al., 2002:538). Hochschild (1983) refers to 'feeling rules' that are socially variable. It is the maintaining of these rules that influence the management of emotion.

We make sense of the world through the rules we are given to understand it. But because we are immersed in these rules and surrounded by them, our world view or cultural perspective are established in us before we have the ability to

recognise or reflect upon them as constructs. These beliefs are imbedded in us. They are part of how we understand and make sense of the world. (O'Leary, 2004:46)

Feeling rules guide emotion by establishing a sense of entitlement to that emotion (Holstein and Cubruim, 2003). In the context of caregiving for a family member with a terminal illness emotional labour is reported as significant (Exley and Allen, 2007; Payne, 2007; Thomas et al., 2002). The discussion is informed by caregivers withholding responses "*I can't cry*". "*Being as brave as anything*". When the caregiver is alienated from expressing, feeling or even identifying their own emotions in the hope of protecting another, the caregiver is performing emotional labour. The containment of emotion may be challenged when the reality of the loss is recognised. Grief in bereavement is culturally associated with the expression of sadness, grief and loss.

Grief

The corporeal self is the housing for emotions and the physical, cognitive and behavioural manifestations of grief. Grief is a normal and natural response to loss and change. A frightening but normal range of emotions may be experienced. As discussed in chapter three, the responses to grief are not limited to bereavement: caregivers experience grief along the illness trajectory as they accommodate changes, loss and adjustment to illness

Sometimes I would get angry at the thought that, you know, that this should happen

Mavis - caregiving interview

Emotions experienced include sadness, anger, guilt, anxiety, loneliness, relief and sometimes an absence of emotion or feeling, such as numbness. The old-fashioned term 'pining' is one that I have heard employed by a recently bereaved partner.

After I got over the shock ... it took me a minute or three to get over the shock...

Jennifer - caregiving interview

While many of these emotions are experienced in the period immediately after a death, researchers and grief theorists such as Doka (2000), Rando (1991), and Worden (1991) conclude that such emotions may remain in varying intensity for a long period of time. As described in chapter four of this work, the bereavement interviews took place approximately 2-3 months after the death.

Cognitive changes due to grief are also well documented. Confusion, disbelief, preoccupation and compromised memory are features of thinking patterns altered by grief. Reports of absent-mindedness are frequent

You are in a state. You are not in touch, I don't think, with reality. You might appear to be, but I don't think you really are. I was lost ... I found that I couldn't really engage in anything. I couldn't watch TV, you can't read a paper, read a book, do anything like that. It took me quite a number of months to be able to sit down and watch TV.

Jennifer - bereavement interview

I think I didn't completely take it in until ... [month] this year

Catriona - caregiving interview

I can't remember too much in the way of details...

Catriona - bereavement interview

The presence of both auditory and visual hallucinations is sometimes experienced by grieving people. This can manifest itself as a sense of the deceased person's presence. Jennifer recounted how she "*feels close*" to Jimmy both in her home in Wellington area as well as when she visits the grave. For her, there is comfort and sense of connection with him, as the vignette described in this chapter's section on space.

Corporeality - of the body - registers profound physiological changes in grief. Exhaustion, fatigue and weakness are not only present in those experiencing grief, but also may be resultant from the period of interrupted sleep, constant attention and hyper-vigilance associated with caregiving.

I have days when I feel very tired you know, that's just part of it.

Mavis - caregiving interview

Jennifer, in describing the physical exhaustion of bereavement, seemed to re-experience the effects of depleted energy even in her speech. In the following transcription her language becomes sparse, the second sentence lacking pronouns, as though the truncated speech reflects her experience of her tiredness

... I went back to work but I was exhausted by it. Functioned on certain levels. It puts your mind in a different space

Jennifer - bereavement interview

Behavioural features of grief are manifold, with disruptions to sleep and eating patterns distinguishable. Social withdrawal or the need for social withdrawal occasioned by uncharacteristic irritation is described by Catriona

I needed to do that [get out] because I was starting to get snappy and I knew I shouldn't be

Catriona - caregiving interview

The physiological stress for caregivers has been noted as 'vicarious suffering' (Payne, 2009). Mavis experienced physical health issues that she attributes directly to the grief and stress of diagnosis

I suppose it was the stress or trauma or whatever, that let it out

Mavis - caregiving interview

Grief is often associated with the behaviour of crying. During interviews with three of the four participants, tears were present. The issue of participants becoming distressed during research interviews is commonly linked to the notion of causing harm as reported by Appleton (2004). This will be further explored in the final chapter of this study where other ethical issues are addressed. My experience of witnessing tears during an interview is summarised by Appleton "Individuals are merely expressing what they are feeling and it is not a result of the interview itself. Participants are more likely to be distressed by [dying] than by talking about it" (2004:269). Sighing and crying are possibly the archetypal indicators of grief

I was crying and I wasn't anywhere near him

Mavis - caregiving interview

Summary of theme: corporeality – the lived body

This first section of corporeality has discussed the existential lifeworld theme of the 'lived body' as it relates to the caregivers in this study. It has detailed the physical do-ing of caregiving. It has also detailed the

emotional being of caregiving. This section discussed corporeality as the lived body of the caregiver in both the physical and emotional. It concluded with physical, behavioural, cognitive and emotional manifestations of grief. The focus of the second section is relationality - the lived other.

Section 2 Relationality - the lived other

Introduction to concept

In this section the experience of caregiving for a terminally ill family member and the subsequent bereavement is examined from the second existential lifeworld theme - the lived other. Van Manen describes the lived other as "the lived relation we maintain with others in the interpersonal space that we share with them" (1990:104). Family members undertake caregiving while mediating a nexus of complex relationships: the terminally ill person, other family members, and finally with health professionals. Changes in the balance within family relationships affect the family system and lead to role change (Reith and Payne, 2009). Using the theme of the lived other, the changes in existing relationships and the development of new relationships with health professionals are examined.

Relationship with the terminally ill person

Existing relationship: Caregiving for all the participants arose out of an existing relationship previously defined by mutuality, out of a natural extension of family relationships (Hudson and Payne, 2009; Reith and Payne, 2009). Jennifer re-defines the term 'caregiver' removing the professional context. To her, she was a 'caregiver' because she 'cared,' demonstrating caregiving was predicated on the existence of emotionally intimate social relationships (Exley and Allen, 2007). In the study of caregivers of women with cancer (Bernard and Guarnaccia, 2002), the

nature of caregiving is noted to foster added intimacy or be the result of added intimacy in the caregiver and patient relationship

I don't know ... I don't know because you are always the caregiver ... um ... he has always cared for me and I have always cared for him ... so it's not been a matter of taking it on ... it's something that we have done together. I view myself as his wife...

Jennifer - caregiving interview

We are very much trapped in our sort of traditional roles. She is the older sister and I am the one who does what she is told ... It's a development in our relationship

Catriona - caregiving interview

Catriona continued to evaluate her role based on the sisterly relationship, even immediately after the death, when she assisted in laying out the body. Her consideration appeared to be based in part on retention of her sister's privacy

[the nurse] sort of looked at me, and looked at J and I thought I would be the more suitable one

Catriona – bereavement interview

I was very aware that she found my care easier to live with than anybody else's, because I knew what to do, partly because of our shared history...

Catriona – bereavement interview

Mavis expressed the expectation that she should be the one to undertake the caregiving role, that it was based on the desire to share with the partner, to demonstrate love and concern (Ellis-Hills and Payne, 2001). For some, there may be no distinguishable

point where the family or spousal relationship changes to 'patient' and 'caregiver', but rather caregiving evolves (Pierce, 2006).

I felt that it was expected of me ... I felt I should be able to...and ... well ... I should do it ... it should be me that's doing it. I kept thinking that he probably wouldn't want someone else to do it ... he just said 'you stand by and make sure I'm alright'... He was sick and if I was sick he would look after me.... I think most people would do that, don't you think?

Mavis - caregiving interview

Pre-existing relational ties may automatically render a person a carer, whether or not they are able to perform that role (Payne, et al., 1999; Payne and Ellis-Hill 2001). This is germane when reviewing the caregiver/cared for dyad for older couples; it may be difficult to distinguish caregiving roles where patterns of mutual dependence overlap and fluctuate as frailty and ill health have an impact upon the two individuals (Payne, 2007).

Changing relationship: The very relationship which propels the role of caregiver is changed and challenged as a consequence of caregiving. Relationships may experience role reversal or be compromised. The balance of power and roles alter as one partner becomes seriously ill. The caregiver/ patient relationship may be compromised, especially if the cares are associated with inflicting pain. One caregiver related how a simple blood blister had ended up on the patient's leg, resulting in her concern

I won't touch it ... you know ... because if I did I might have given him a terrible lot of pain

Mavis - bereavement interview

Undertaking the care of another at home may damage the very relationship that it seeks to reverse as the nature of the interaction between the caregiver and the ill person changes (Exley and Allen, 2007). People build their lives in a social context; in relationships that they are part of, and develop expectations of how that life will progress. Death and illness interrupts those expectations (Reith and Payne, 2009).

He had given up mowing the lawns ... he used to do the gardening ... he used to do the vacuuming most Fridays and he would wash the floors while I cleaned ... We sort of shared the housework ... [but now] I have to think of more things that I had only thought of vaguely, like paying the bills.

Mavis – caregiving interview

Similarly, Barbara regrets the loss of role; her husband had become a different man. Barbara had lost the provider, the breadwinner, the home handyman. In expressing the current burden of caregiving, Barbara reflects on what she might have hoped for, a different old age from what she was experiencing. In addition to the existing roles there are new roles that carers take on, including those that were previously the domain of the ill person. This creates the potential for increased workload as new skills are learned (Stajduhar and Cohen, 2009).

... He was always a very hard working man, and then he didn't want to do anything anymore. Bob found it hard because he used to do all that and now he had to hand it over. ... I can't cope with it, I have that attitude sometimes you know. So it's the hardest thing for me ... it's a bit of a struggle you know

Barbara – caregiving interview

Anticipation of bereavement changes the roles. Symbolic losses such as position in the family or role redefinition sit alongside the very real losses of appearance, cognition and functional ability (Cantwell-Bartl, 2006). Caregiving in the context of terminal illness is undertaken with the certainty that the caregiving will end with the death of the other. There is an acute awareness of impending death. The physical changes witnessed signal the transitions that occur and are often accompanied by the fear of loss. Mavis explained her heightened vigilance

I would wake and I would be awake for hours listening to make sure he was still breathing. You know, it's that kind of thing ... the feelings you get inside, you feel helpless

Mavis - caregiving interview

Identity of these caregivers, as related to role, is a theme that has emerged through this research. The final illustration of this is the poignant last phrase from Jennifer where her awareness is of forging a new identity and establishing new relationships as a bereaved person which reflects the task approach of Worden (1982, 1991)

It's my job to find my way as a widow ... that's what I have to do now

Jennifer - bereavement interview.

Relationship with others

Family relationship: Within palliative care practice and philosophy both the patient and the family are construed as the unit of care. The family is both the principal source of support and care but the family also faces the illness (Hudson and Payne, 2009). The notion of caring within families is interactive, as patients also care for and support the family (Kellehear, 2009). Within the family dynamic, Reith and Payne (2009) suggest that

some people want to protect close family members from the reality of loss and grief.

I just stood there and thought 'cancer' and my daughter was standing beside me... and I thought I can't cry it will upset [her] and [she] thought I can't cry it will upset mum. So the pair of us were being as brave as anything about it ... [she said] she cried all the way home, and I basically cried all the way home ... I have never cried at all until Friday ... I was crying, when he was coming in here [into the hospice] he looked so defenceless

Mavis - caregiving interview

Collusion with untruth or protection of another is one feature of some family systems. Where there is an imbalance between both truth and hope there may also be a power imbalance with what information is given, at what time and to whom. Information may be withheld with the aim of protecting another (Reith and Payne, 2009).

[the patient] kept saying the doctors said years and of course I knew the doctors hadn't said years, they'd said months

Name withheld

I think he was more aware than we really thought. He never really let on to us how sick he really was

Mavis - bereavement interview

He insisted everything was alright [3 days before he died]... and of course we had kept how sick he was from our granddaughter. She was doing all her exams, and we hadn't told her so we actually had to tell her and take her

in, [to the hospice] and then she had an exam the next day. It was just so awful

Mavis - bereavement interview

When the family engages in open communication and support the experience is different

...And that's what I mean by... we care for [other people]. I couldn't do that [exclude others]: I cared for him and other people cared for him and cared for me

Jennifer - bereavement interview

Professional relationship: Most people with a terminal illness are cared for at home by family caregivers. Integral to this is the professional support and advice given by hospice or other health professionals. For family members negotiating these relationships can be complex as the sense of indebtedness to professionals vies with the fear of offending (Beresford et al., 2007; Bland, 1994). Health visitors may be perceived as either an expert, as an intrusion, or as a threat to the family system. Couples accustomed to privacy and uninhibited communication may need to adjust their way of being with each other in the presence of a visiting health professional. The professional may gain knowledge about all aspects of family life: indeed may be viewed as intrusive into domestic life (Cantwell-Bartl, 2006). The private becomes public. The alternate construct is that as a source of support, visiting health professionals empower the family caregiver in the execution of their role. Caregivers interviewed for this study articulated both the sense of support from clinicians and the desire to manage the visits of professionals into their homes.

... the district nurses, the back up services with the doctors and the fact that you can call someone in at night .. I find

that terrific so that you don't feel you have to cope on your own all the time, which is lucky because when things go wrong [the patient] loses all faith in my ability or her partner's ability to judge the seriousness of what is happening. She wants somebody with medical qualifications please ... so it is great

Catriona - caregiving interview

Family caregivers did not always experience the level of support they require to continue caregiving at home. Family caregivers did not always get the information needed. Both of these issues are features of caregiving literature audits of the needs of caregivers (Allen et al., 2006; Beresford et al., 2007; Payne et al., 1999)

The doctor said, 'I think it's cancer, you've got x months to live, so we were very worried about it, so my son went outside and the doctor went outside in the corridor, my son went with him and he is talking to him and [the doctor] said, 'I've got no time. I have other patients'. So that was it

Barbara - caregiving interview

I did get cross once or twice when the nurse would say she was coming then did not turn up... They would say 'call us if you need us', and I kept thinking 'I do need you'

Mavis – bereavement interview

This, I believe illustrates a clash of cultures: the culture of an institution and the culture of the domestic. Despite job descriptions or titles reflecting the term 'community', visiting clinicians represent the institution of employment. Routines, equipment, assessments and monitoring are

undertaken or provided in a way that is not always homogeneous with home life. Further difficulties were experienced if caregivers were expected to perform (nursing) tasks outside the scope of their own perceived ability, or decisions were made by professionals that excluded the family. Mavis experienced both: she established clear boundaries in her duties when she was expected to administer medications through a '*shunt thing*' and disagreed with a social worker's plan for care. This evidences an imbalance of power which is a feature of some medical institutions. When there is an unequal balance of power between parties, accepting advice or services may mean accepting the professional as expert, and an obligation to comply (Bland, 1994).

They [the nurses] said 'we will teach you how to use it' and I said 'No you're not. You are coming to do that. I don't want to make a mess of things. You're the professionals'... when it came to medication and things I felt it was their job, not mine

Mavis - bereavement interview

.. I got a bit angry when the social worker said he could come home... I thought you only have to look at him [to see that he is too unwell to be at home]

Mavis - bereavement interview

When caregivers felt empowered, the experience was different. By taking on responsibility and acting as an advocate for the terminally ill person, the family caregiver often becomes proficient at communicating with health professionals (Smith, 2001). Jennifer acted as a strong advocate for her husband.

We said that we would only be there [the hospice in patient unit] as long as we needed to be and I said we

would use them. To me, the hospice is a resource which is aiding the caring for him and it is one of the resources we have available to us and we are going to use it to help us and we viewed it in that light. That's how I saw it and how I wanted him to see it and nothing more ... [when pain was managed] he wanted to be out, so we did, we said 'so you can give us this and this' and they were able to and we were out

Jennifer - bereavement interview

Summary of theme: relationality – the lived other

The second section of relationality has discussed the existential lifeworld theme of the 'lived other' as it relates to the caregivers in this study. It has detailed the complexity of relationships that family members negotiate with the terminally ill person. The caregiving role has been demonstrated as having its genesis in the relationship: both the existing nature and the changing nature of the relationship have been outlined where the dual constructs of reciprocity and duty have been examined. Relationships with others, including professionals have been discussed, where the notion of obligation and protection have been examined. The focus of the next section is the lived time.

Section 3 Temporality - the Lived Time

Introduction to concept

In this section the experience of caregiving for a terminally ill family member and the subsequent bereavement is examined from the third existential lifeworld theme - the lived time. Van Manen describes the lived time writing "temporality is the subjective time as opposed to clock time or objective time" (1990:104). The existential concept of temporality is the

way a person lives simultaneously in the present, is influenced by the past and is projected in the future (Benner and Wrubel in Bland, 1994: 78). This is of particular significance when caregivers and the terminally ill person have limited time together. Brevity of remaining time and the transitions that occur bring with it a sense that there is no second chance to 'get it right', that the experience cannot be altered or repeated (Payne and Ellis-Hill, 2001; Lowery, 2008). The demands made of caregivers are time consuming: however, the caregivers' perceptions relating to time are more complex than being either 'limited' or 'disrupted'. The concept of time as a phenomenological theme forms part of the phenomenologist Heidegger's view that all time moves inexorably towards death (Rose, 1998). Using the theme of the lived time, uncertainty of time and of any future, time demands on caregivers and life interrupted are examined.

Uncertainty of Time

Time suspended: Caregiving in the palliative care context is underpinned by the notion that the caregiving role will end on the death of the terminally ill person. Carers face considerable uncertainty over the length of time for which they are committing themselves to care and what may be involved in delivering that care (Ingleton et al., 2003). The period of caregiving remains uncertain. Caregivers frequently put their own lives on hold in order to be available. Strang et al.(2002:97) use carers' experiences to describe a world "set apart from everyday life patterns" in an unreal, suspended cocoon-like world.

Because you don't know how long it is for, it's terribly hard to ... you know, you can't plan your life. I know it seems awful to think you wish she would get on with it [dying] but sometimes you do. So you just have to try to live for today ... You have no idea of how long this is for

Catriona - caregiving interview

[On diagnosis] we came home, and our daughter came from overseas and we thought it was going to be a few months.. so we had a family gathering here ... well I never thought it would be like that ... we were told it would be only a few months ... It's not knowing what the future is going to hold, or how long it is going to take. I did not know how long it was going to be like that. It's hard and I guess I find it hard doing it now

Barbara - caregiving interview

You are in a state. You are not in touch, I don't think, with reality...

Jennifer - caregiving interview

Time limited: Brevity of remaining time, the intensity of time left and rapid adjustments to the transitions are particular features of caregiving within the terminal illness context (Payne and Ellis-Hills, 2001; Strang et al., 2002).

The caregiving period is, by definition, likely to be shorter than for a chronic or dementing illness. Opportunities for the development of new skills and coping strategies are equally time limited (Harding et al., 2004). Because of the sometimes rapidly changing disease process, caregivers are required to rapidly adjust to the needs. This may mean learning new skills in the midst of a crisis. The losses, which are losses on many levels, are experienced over a shorter period of time (Pierce, 2006).

It's just the skills needed [to care for him] and what he might need changes.

Jennifer - caregiving interview

I learned the routine of just going slowly and thinking about what they might want and judging from facial expressions and fidgets and whatever to indicate that people are tired or people need pills or that kind of thing.

Catriona - caregiving interview

Even though time was limited, the participants acknowledged that providing care to a terminally ill person allowed adjustment to impending death. Some described this time as special. "Caring for people when they are dying will always be one of life's most challenging privileges" (Kovacs, 2006:25).

... in witnessing these poignant moments, things that you are party to. They are precious moments. Those are amazing things to witness. You don't get the chance again and they come from people's heart and you get to see them.

Jennifer - bereavement interview

I feel as though I had a fair amount of time to think about it as I went along ... definitely think it has made me accept ... because I had plenty of time to get used to that thought [of death]

Catriona - bereavement interview

I think these past few days, I think I have realised just how close he could be ... much more ready to [pause] accept [pause] things, I think now

Mavis - caregiving interview

The temporal nature of caregiving bears witness to time. People pass through many transitions: becoming a carer, being a carer and no longer being a carer (Sheldon et al., 2001)

Timed right: Time was also described by participants, not only in the abstract sense but in the real clock sense of time. The relationships with health professionals as detailed previously represented a 'tie-line' between hospice and home (Smith, 2001). Participants realised the importance of timing things 'right'. On occasions this relied on the expertise of professionals. When supplementary care was required Catriona's experience was of being supported by hospice and other nursing staff

[the hospice nurse] *timed it just right, because* [the patient] *started to need help in the night ...* [the hospice nurse then arranged for an overnight nurse] *we had an excellent agency nurse ... then the nurse said 'I think you should come in and see her now' which we did and we just held her hand and she died in about 20 minutes I suppose.*

Catriona - bereavement interview

Mavis described the final moments, when she was absent. In this instance the timing was 'ill-timed'

They rang us to come down. I had to make a quick trip to the toilet, and I sort of pulled on my clothes and got down there [in about one or two minutes] and he was dead before I got there

Mavis - bereavement interview

Demands of Time

Time pressured: Informal caregivers within a cancer context are more likely to provide more complex care (Nijboer et al., 2000). Demands on

carers stem from a variety of sources including the amount of time spent, and recognition that cares take longer when the patient's energy is depleted (Payne and Ellis - Hills, 2001; Rose, 1998). The demands made of caregivers are time consuming as illustrated by these participants, whose own schedule was interrupted or restricted (Payne, 1999). The 'burden' of caregiving was evidenced in the caregiver anticipating the next phase, or 'second guessing' (Docherty, Owens, Asadi-Lari, Petchey, Williams and Carter, 2008). Caregiver 'burden' refers to the negative feelings that may be experienced when giving care (Nijboer et al.). Caring is generally perceived as hard work, although consistent to the findings of Skilbeck et al., (2005) caregiving was something undertaken willingly despite the difficulties experienced. It is noteworthy that difficulties and satisfaction for caregivers are not necessarily diametrically opposed (Nolan, 2001).

He was very difficult to understand and speaking was a great effort. It took him a long time to do it ... I still managed his care over the day with washes and caring for him, because I was here [at home] all week

Jennifer - bereavement interview

It has been almost fulltime [caring for him]. You can't plan on doing anything. You have to wait and hope that he will be well enough that you can leave him for a wee while and go out ... then he would sleep for two to three hours... which was good because I could potter round and do

things and sometimes I would get out

Mavis - caregiving interview

I used to organise all those things ... who else is going to do it? I can't sit down, who else will do it, who else will do

all those things ... I think a lot about those things ... I would think ahead of what needs to be done and do it

Barbara - caregiving interview

It wasn't running around so much in that he was demanding things all the time, it was the fact that he would sit there and he would wait for me [to do it] ... So I would drop whatever I was doing and I would get things...

Mavis - caregiving interview

Time lost: Family caregivers experience and mourn many losses (Pierce, 2006), including relinquishing what might have been. Throughout the caregiving, spouses begin to experience the loss of the relationship (Bernard and Guarnaccia, 2002). The future together is a time that is lost to the participating interviewees, where the relationship is based on a past history or biography. It is not only "*whom we have lost* but *what we have lost in them* " (Leader 2008: 34, italics original). Grollman (in Doka, 1993) noted that when one loses a parent, one loses a link with the past. When one loses a partner one's present is challenged. When one loses a child one's future is altered. The participating interviewees in this study articulated this profound sense of loss of the future.

I don't know what kind of a relationship it would be.. it's just we can sit in the same room for two or three hours... and we didn't have to say a word to each other... we are very comfortable with each other, you know, friends ... We have been married for x years and now it has gone

Mavis - caregiving and bereavement interview

I was very lucky that I was able to do this... I think that the way that I cared for him has been exemplary from the

point of view, that it was very, um, ... I had certain things that we could do ... that I didn't want to lose him

Jennifer - bereavement interview

Interwoven with this is the existential questioning of 'what if'. As well as reviewing their past together, Mavis reviewed the chronological timing of treatment

I kept wondering, if we hadn't had to wait that four or five weeks [for treatment] ... if he'd had that appointment then ... I kept thinking that all that may not have happened ... things could have been different. Those are the 'what ifs'

Mavis - bereavement interview

Summary of theme: temporality - the lived time

This third section of temporality has discussed the existential lifeworld theme of 'lived time' as it relates to the caregivers in this study. It has detailed both the demands and uncertainty of time. For family caregivers, time suspended and time limited have been discussed and analysed with reference to caregiving literature. The 'burden' construct has been examined as relating to the pressure and busy-ness of caregiving. Aspects of 'burden' relating to emotional labour have also been reviewed in 'the lived body'. Finally, the fragility of time has been viewed: the loss of a future and the 'what ifs'. The focus of the fourth and final section is the lived space.

Section 4 Spatiality - the Lived Space

Introduction to concept

In this section the experience of caregiving for a terminally ill family member and the subsequent bereavement is examined from the fourth existential lifeworld theme - the lived space. Van Manen describes the lived space as "felt space ... we become the space we are in" (1990:102). The concept also of geographic place as space is justified as congruent to the existential theme of spatiality. Most care received by terminally ill people occurs at home. This means that 'home' for caregivers may be both a place of refuge and place of stress. Van Manen argues that the experience of lived space is largely pre-verbal, yet the meaning we ascribe to space affects the way we experience the world: having something to do with the fundamental sense of being (ibid:102). The aesthetics and meaning of 'home' is then analysed in conjunction with the caregivers' data. Finally geographically located language is then examined as the metaphor for the world, landscape or experience that the participants encounter.

Home as Place

Private: Home has been described as the secure inner sanctity where people can feel protected and be ourselves; where we can *be* what we *are* (van Manen, 1990: 102). The use of the term 'home' is as a concept as well as a physical place. In the context of caregiving, the private space of home is both compromised and expanded: confining if one can't leave the patient, and inclusive to accommodate professionals and equipment. Implicit in home care is the assumption that home is a social space where individuals are relaxed and at ease and privacy can be maintained (Exley and Allen, 2007). Privacy emerges as a central defining feature in the meaning of 'home'. In conveying the news of Jimmy's diagnosis to him, Jennifer intentionally chose the home space to talk.

I realised I ought to tell him [of the histology results I couldn't think of anybody better to tell him. And I wanted to do it here ... so I called him home

Jennifer - caregiving interview.

The private meaning of home is further emphasised by both Jennifer and Catriona. The home remained a haven for those they cared for; both patients responded differently in their own homes from their behaviour in the in patient unit of the hospice. Home had become an extension of the self in material surroundings (Exley and Allen, 2007).

The hospice was making suggestions that she go home as long as she could be cared for at home..... I was there when she came home and saw how much she cheered up ... she's [now] happy and eating and getting on like a house on fire.

Catriona - caregiving interview

The day we took him home we wheel chaired him out to the car ... because he just had to go [home]. We took him home and pulled up in the driveway [we were to get the wheelchair out the car as he could walk only a short distance] ... he just left us and walked all the way down the zig-zag [path, (about 60 metres)] into the house and sat down. I thought that if he had stayed [in the hospice] he would have died

Jennifer - bereavement interview.

Home can be a place of refuge for the terminally ill person, but confining to the caregiver. Social activity may be curtailed as the ill person's care

requires more time, increased frequency, or is unable to be left alone, or daily routines are established around appointments.

...her partner does not live in the house but he arrives each day at about midday so that means in the afternoons I can go out for a walk

Catriona - caregiving interview

I had to be there. The fact that I could never go off and go out..

Mavis - bereavement interview

But those things [outings] are finished now... he doesn't go out any more. It has all changed

Barbara - caregiving interview

The provision of intimate bodily care is a feature of caregiving. As noted, this has the potential to change the existing relationships. It also may challenge the meaning of 'home'. When the private home space is reorganised around the needs of the ill person, some cares may occur in what was previously communal space. A bed and commode may be accommodated in what was a sitting room. This private haven of home is compromised with the relocation of equipment to the home. When the home also becomes the workplace and the care of the family member becomes the 'job', the boundary between private and public life is blurred. The private becomes public as social and personal boundaries are transgressed.

Public: One alteration to the lived space occurs because of loss of privacy. When caregiving is relegated to the home environment, there occurs a fundamental change in the meaning of home (Exley and Allen, 2007). Privacy may be hard to achieve. When death occurs in the home, death becomes part of life, of family or community rather than hidden

away (Aries 1981; Hera, 1995). As noted earlier in this chapter, health professionals become privy to what were previously perceived as private matters. Catriona appeared keenly aware of her sister's private home life. In bereavement it appeared she continued to guard her (deceased) sister's privacy.

It was extraordinary what we found in cupboards... I mean you're seeing past the public face of somebody really. I sort of came across a few things and thought 'Hmmm... interesting'. I quietly disposed of the odd thing myself, but thought 'that's for me not anybody else to see'

Catriona - bereavement interview

Home as Space

Aesthetics: Alterations to lived space occur in the home when caregiving for a terminally ill person. The aesthetics of home are changed. Most houses are not designed to accommodate the needs of a frail or terminally ill person. The importation of medical or specialist equipment changes the personal significance of home. Control over the aesthetics is relinquished as caregiving for a terminally ill person frequently requires equipment necessary to support care at home (Exley and Allen, 2007), the introduction of hospital beds, commodes, hydraulic hoists, wheelchairs and other aids and appliances. These are relocated from the institutional setting (the hospital or hospice) into the private, domestic space that was 'home', imposing organisational restraints in the domestic setting. Consideration of equipment into the home may affect the meaning of the physical environment. Although not canvassed by any of this study's participants, hospital equipment may remain in the home for some time following the death. For some families its continued presence is a reminder of what has been lost.

Alterations: Home death alters the meaning of 'home'. When death occurs in the home, death occurs in the midst of living (Aries, 1981; Hera, 1995). This appears to uphold the palliative care philosophy that 'death is part of life' and therefore to be a virtuous aim. Family members will often continue to inhabit the space once the patient has died, highlighting some inherent tensions as to how the experience of death will impact upon their sense of wellbeing. Jennifer's husband died at home, in which she takes comfort in bereavement.

The meaning of home has changed ... it has indeed. For me the meaning is closer. I feel close to him because he died here. I always looked forward to coming home... there was a sense of him... the ways... the times that you had with him... all those times that you shared together

Jennifer - bereavement interview

For the caregiver or for other family, the shared biography of a life together is interrupted by death. If this death occurs in the home, the space where people feel protected, the meaning of that space may be ascribed with malevolence.

But one of the negatives that has come out of it, is that it is very difficult for his children to come round [to the house] because this is where they associate with, that is ... their current memory that they have and associate with their dad. And his family ... they come to see me but not at the house

Jennifer - bereavement interview

Final memories of the bereaved caregiver may be situated in the familiar environment. Due to physical changes in the dying person, this familiarity of environment may be juxtaposed with the unfamiliar appearance of the

patient. The final images of the person's frailty immediately before death, or the recalled picture of the person after death may be enduring for those who remain in the home. The memory of the death at home is reinforced by the familiar environment where the deceased is missing (Worden, 1991).

Journey as metaphor

Spatiality refers to the lived space, the space we inhabit. In the context of family caregiving, the discussion on spatiality has been on the practice of 'hospice at home' or home care. The concept of home and the meaning of home space have been explored. However, in this segment, Journey as Metaphor, I wish to examine another aspect of spatiality - that of place. The language used by participants has been arresting precisely because of its metaphorical link with place. I wish now to explore this further. Phrases such as:

'on this journey',
'blip in the landscape',
'I was lost'
'you are in a state'
'going downhill'
'come along behind and tidy up'
'[things] get on top of you'
'bend in the river'
'in limbo'
'in the distance'

These phrases all used by the participants are distinctly locational; as though these caregivers, in the unfamiliar territory of caregiving, used language to place themselves geographically in order to make meaning or sense of the experience. For those who experienced caregiving as burdensome, there appeared to be little subtle distinction between 'being on a road' and 'being in a rut'. It is as though the future (temporality-time)

is located in 'the distance' (spatiality-place). One participant (name withheld) demonstrated in both interviews a strong sense of place, as though her memories of the person she cared for were anchored to the landscape. She appears to be geographically located, mapping out her experience of the everyday: in the house, in the street, in New Zealand. A feature of the interviews is her frequent references to places when recounting events. In bereavement the person she cared for is now missing from all the places. Once the bearings go, one becomes 'lost'. Prior to that, she measured the illness progression of the patient in terms of how far the patient can walk

For a while X was able to walk about 100 yards up the road and come back and walk about 50 yards down the road and back inside.

Name withheld

When describing a previous caregiving role, even the family relationships were described geographically as she tried to recall event sequencing.

I had a brother who ... and my other brother was [pause] where was my other brother?

Name withheld

It is as though the geography of the landscape will provide a map of the territory of the illness. Once the landscape has been 'darkened' by a diagnosis of terminal illness, the territory becomes unfamiliar or unrecognisable. The 'darkness' of disease is frightening. In palliative care and illness literature, the term 'journey' is frequently used. The premise of a journey is that there will be a destination, an end. When terminal illness is the 'journey' the destination is the death. For the unnamed participant, this was not discussed between them, making the journey perhaps more frightening, with a greater reliance on the 'signposts'.

The complexities of 'navigating' the health and social care systems are imbued with metaphoric language associated with travel. People look for 'signposts' on the 'journey'. Sontag in her work "Illness as Metaphor" (1991) employs the paradigm that we require passports in order to move between the world of the healthy and the world of the sick. Similarly, to negotiate the illness and subsequent bereavement, the language employed by these caregivers is frequently that of geography. People, equally, draw on external signposts in making sense of illness. It is as though a map is required. The map then becomes the tool to understanding and making meaning of illness and death.

Summary of theme: spatiality – the lived space

The final section of spatiality in this chapter of data presentation and analysis has discussed the existential lifeworld theme of the 'lived space' as it relates to the caregivers in this study. It has detailed both the physical space of home care and examined the geographical language used by caregivers in describing a 'journey'. For family caregivers, home is not merely about the physical space but the social and emotional relationships. These concepts have been reviewed with reference to caregiving literature. Hospice at home has been examined as relating to the changed nature of the meaning of home.

Conclusion and Discussion of data

This chapter has detailed the experience of family caregivers caring for someone with a terminal illness. I have both presented and analysed the data, interwoven with discussion on the four existential themes as outlined in phenomenological research. Firstly corporeality, the initial section, examined the impact on the body of the caregiver; including the construct of emotional labour as well as physical demands. Secondly, relationality examined the nexus of complex relationships negotiated by the caregiver with the terminally ill person, other family members; and finally with health

professionals. Using the theme of the lived other, the changes in existing relationships and the development of new relationships were discussed. Thirdly, temporality examined the concept of time, which is of particular significance when caregivers and the terminally ill person have limited time left together. Using the theme of the lived time, uncertainty of time and of any future, time demands on caregivers and life interrupted were discussed. Finally, spatiality examined the significance and meaning of 'home' which was then analysed in conjunction with the caregivers' data. This section concluded with a discussion on the use of spatial language as a means of making meaning of experience.

The provision of palliative care has unique features: profound interpersonal and caregiving complexities, acute medical and relational changes and disease unpredictability set this arena of caregiving apart from long term care. When the provision of palliative care is relocated to the home, emotional, interpersonal and contextual implications are brought into sharp relief. The complexities of the meaning of space, time, and interpersonal relationships are sometimes accompanied by tensions which are amplified in the domestic setting.

In the initial literature search undertaken there appeared to be a paucity of research specific to the palliative care context. The reasons for this are documented in this paper: some research omits palliative care in the title, this area is only recently gaining recognition in research and academic circles and ethical debates previously discouraged research for dying people and their families (Beresford et al.,2007; Munroe and Oliviere, 2009; Payne, 2003). I therefore drew on the wider literature on carers of adults with chronic diseases to consider the role of the caregiver. It was from this that I developed an understanding of the 'burden' construct that has been referred to in this chapter. The presentation of caregiving being a burden emphasises the negative aspects of caregiving, based on a pathological model of coping. It remains uni-dimensional. Instruments to

measure the 'burden' focus on the observable tasks, predominately personal and domestic caregiving. The all encompassing term refers to physical, financial, emotional and social costs of caregiving and does not consider or minimises the reciprocity, the shared history and the pre-existing ties. By emphasising a pathological model it fails to capture sources of satisfaction and reward, or the dynamic and evolving nature of caregiving for someone with a terminal illness. Because of the time limited nature of caring for a terminally ill family member, the burden construct maximises sacrifices and minimises gains. The application in the terminal illness context remains ambiguous. The participants themselves present dual sympathies in their narratives.

The importance of interviewing caregivers cannot be overlooked. Firstly, there is a moral imperative to acknowledge the experiences of service users. There is something in the narrative of the word spoken that leads to a greater insight of the lived experience (Powers, 2008). The meaning of the text is oral, in that the interviewee is speaking out words. Leader (2008) contends that grief needs others to bear witness to it; the bereaved need to tell their stories. For caregivers, whose grief is not that of bereavement, but of decline, change, impending death and a future lost, there are limited avenues to tell their story. Story telling gives voice to a portion of humanity (Powers). These caregivers, by recounting their experiences, have revealed the way their world has been impacted on. By the analysis of transcripts I have attempted to find a thread that binds each fragment together and to give sense to it. I remain mindful that language is the main tool of the social work trade (Schofield, 1999). Niemeyer (2006) maintains that individuals make sense of loss by constructing and reconstructing a narrative, choosing narrative as a means of organising their experiences and giving them meaning. 'Jennifer' has been introduced with other participants. Her New Zealand Māori heritage places her firmly within an oral tradition. The use of narrative has recognised the place of such tradition.

This study utilised phenomenological methodology to make visible the realities of caring for someone with a terminal illness. Semi-structured interviews guided the participants in reflecting on that experience, to talk about their reactions and impressions. These narratives detail the complex ways in which these women identify as a caregiver and forge a new identity for themselves in bereavement. The participants in this study provided a clear narrative to support the four phenomenological life world themes of corporeality, relationality, temporality and spatiality. Triangulation with other sources was achieved in that the data findings in the research literature around the dual construct of burden and privilege was consistent between the interviewees.

Concluding Overview

This study has elaborated the lifeworld, the lived experience of these study participants who undertook caregiving for a terminally ill family member. The burden/privilege construct has been demonstrated to impact not only on the individual but on the way they experience their assumptive world that has been challenged by loss. The study participants expressed their reflections on caregiving. Using phenomenological themes as cited by van Manen (1990) this chapter has presented and analysed the lived body, lived relationships, lived time and lived space as described by the four caregivers.

CHAPTER SIX

CONCLUSION

**Death be not proud, though some have called thee
Mighty and dreadful,**

"Death be not proud"

John Donne

Chapter 6 Conclusion

Introduction

The purpose of this final chapter is to review the research project, the research process and the data analysis. I also reflect on the parallel process I perceive between caregiving and thesis writing, that of constructing the narrative, making meaning (Neimeyer, 1999). I explore suggestions for future research that might be undertaken to extend the current knowledge as well as presenting limitations of this study. Larkin, (2008) emphasises the absence of studies such as this one that focus on exploring former caregivers experiences: bereaved caregivers are discussed within the chapter. The chapter also addresses some of the difficulties that arise in palliative care research, including a discussion on the many ethical considerations. The chapter concludes with a reflection on the clinical, including practice, implications of the findings.

Review of the research project

The previous chapter has detailed the experience of the four participants whose lives have been significantly affected by undertaking caregiving for a terminally ill family member and their subsequent bereavement. My interest in this topic stemmed from my work as a clinical palliative care senior social worker in a hospice multi disciplinary team. The two threads of this thesis are reflected in my work as a palliative care social worker: support for the family during the illness and bereavement support. The choice of this topic is informed by three major factors. The first is my own experience as a social worker working with terminally ill people and their families. I have been deeply affected by stories that clients have shared with me and the degree of resilience they demonstrate in harrowing circumstances. The second factor influencing my choice to study in this area is the jurisdiction that social workers have when working with family members and the bereaved. Working as an allied health member in a multi

disciplinary team, the dominant discourse is often bio-medical. Bereavement support and close support of family members is the un-negotiated work of the psycho-social team members. The third reason is the demographics of life limiting illnesses. With an aging population, there is an expected increase in the prevalence of those who will be cared for by a family member. Because of these demographics,³ the role of those carers is on the political agenda in the Western health and social care system. In combining both the experience of caregiving and the experience of bereavement, I have the opportunity to reflect on the dual threads of my role as a palliative care social worker.

This study utilised phenomenological research methodology to reveal, to make visible, the experience of these four caregivers. I was investigating the experience of caregiving, its history, its landscape, its meaning. Semi-structured interviews allowed the participants to explore their experience, the meaning they made from caregiving and reflection of that caregiving in bereavement. A narrative approach guided the data collection. When clients tell their stories to social workers the application of both theory and practice allows us to unpack the way that family, structural and illness discourses have affected their lives. We then link private troubles to public issues. For the women interviewed, the re-telling has been a way of finding, of uncovering, strong and enduring stories. This thesis is a confluence of the individual narrative of caregivers and the wider political and health arena in which this caregiving is situated.

The research question was formulated at the outset of this project and framed the wording of the ethics application, supporting letters and the information participation sheet (Appendices 9, 10, 1, 2 and 3). The aim was to enquire deeply into the experience and subsequent bereavement of family caregivers. During the process, I uncovered layers of meaning that

³ While I recognize the incidence of caregivers for children with a terminal illness, I have not included this very different client group in my research.

those caregivers attributed to their role. During the progression of interviewing, analysing data and drawing together the 'strands of identity' I reflected frequently on the original question. Causal links between caregiving for a terminally ill family member and the experience of subsequent bereavement have been set aside in preference to the examination of the two phenomena. This illustrates the evolving nature of a research undertaking.

Caregiving and thesis - parallel process.

Both caregiving and qualitative research experiences involve a process of evolution. Research evolves and is process oriented (Franklin and Ballan, 2001; Holosko, 2001). I have utilised the term 'parallel process', as a descriptor of similarities of my own experience as a researcher and the experience described by the participants. The term is derived from psycho-analytic paradigms in which the therapist can see a parallel with their own life and experience and that of the client. In this process, the emotions expressed by the client are a reflection of those felt by the therapist toward that client. (Searles, in ten Tusscher, 2006: 76).

Evolving nature: Qualitative social work research allows the method to unfold during the course of the investigation, when questions are addressed once the research is underway.

Concepts ideas and questions that guide their work often emerge during the course of their studying ...to what they are observing, not to pre-ordained theories or beliefs. (Holosko, 2001: 267-268)

In this same way, the role of caregiving is an evolving role, where the demands on the caregiver incrementally increase as the terminally ill person becomes more dependent. Like the process of undertaking qualitative research, knowledge about the next step to take in the process

may be obscured until it is time to take it. Caregivers report that they do not necessarily have an understanding of the undertaking or the time they are committing to, but rather that the role evolves and emerges. Jennifer referred to the evolution of this experience as encountering “the next bend in the river,” as she described how they “didn’t know what we were going to find until we got to that point”. When using this analogy of the river Jennifer acknowledged that at times “the bend” was familiar - they had experienced something that “looked like this” before, and so knew what to do. Jennifer went on to describe how, “sometimes we didn’t know what was coming, so we just had to trust each other”. A familiar expression that palliative care specialists hear from patients or family members regarding dying is “I haven’t done this before” as a way of explaining felt inadequacy. At the time of caregiving, hindsight is no good to them. These expressions indicate the evolutionary nature of the caregiving role and the degree of felt incompetence that this role can engender. In the context of undertaking a Masters of Social Work thesis, these expressions are equally applicable to the evolving nature of research.

Language: Another aspect of the parallel processes between caregiving and research is terminology. The term ‘journey’ is often used in a palliative care/illness context, referring to the trajectory of the illness. The metaphor is commonly used by service users of palliative care. It is also an overworked but accurate metaphor used in the context of thesis study. An oft used phrase is to ‘trust the process’.

Responsibility: The third parallel that I perceive centres around the pending and actual sense of responsibility. When caregivers take advantage of a break from their duties with respite care or carer relief, the intent is that the terminally ill person is cared for in totality by another. However, many caregivers report they remain physically absent, but psychologically present with the terminally ill person. The capacity to ‘switch off’ is limited, as their concern remains for and about the patient. This seems to me parallel to undertaking post graduate study, when even disengaged from study, at some level, my thinking remains on the content

and progress of my writing. As referred to earlier, the term I use with family members is the 'mantle of responsibility', which many caregivers find a helpful analogy to the ever-present consciousness of the patient. This 'mantle' is also felt by those undertaking study, who remain conscious of the research question whilst undertaking other responsibilities. When one's work occurs in the domestic setting, the concept of 'work/life balance' is imbued with ambiguity. Boundaries between 'work' and 'home' become difficult to maintain in both the caregiving and extramural postgraduate undertaking.

Palliative Care Research-Ethics Discussion

The palliative care approach enters people's lives at a time of vulnerability and hospice care of a dying person and bereavement support can engender a sense of indebtedness to the professionals involved. Awareness of this guided my participant recruitment process. The sensitivity of written information was also paramount. Autonomy of participants in deciding or being denied the opportunity to decide whether to participate in research is contentious: there is ongoing debate in the literature of the ethics of involving terminally ill people or their family members in research. The purpose of this section is to highlight the practical, methodological and ethical issues of conducting research in a palliative care context. Ethical challenges are reflected upon, debated and discussed, not with the intent of furnishing solutions but to illustrate the complexities and to broaden the debate of research in palliative care. In this research project, I encountered many of the ethical challenges noted in the palliative care research literature.

Views differ as to whether people facing the terminal phase of illness and/or their caregivers should be involved in research. User involvement is now an internationally established feature of health and social care service

planning and delivery. It has, however, been argued that the palliative care population are vulnerable and should be protected because research could be intrusive, distressing and time consuming or that people who rely on health professionals for care may fear that care could be compromised (see the discussions in Agnew and Duffy, 2009; Appleton, 2004; Beresford et al., 2007; Dean and McClement, 2002; Gysels, Shipman and Higginson, 2008; Reid, 2009; Rolls and Payne, 2008). In a counter-argument academic writings have called for more novel, qualitative exploratory studies into patients' and their families' needs in advanced cancer (Clark, 2003; Kendall et al. both cited in Reid, 2009).

Existing research into user involvement in palliative care suggests that it is appropriate to canvass the views and experience of service users, evidencing that it is not only appropriate but also important to involve those who are in receipt of palliative care services (Agnew and Duffy, 2009; Appleton, 2004; Beresford et al., 2007). User involvement is integral to service development and improvement. Agnew and Duffy (2009) note that apart from the development of satisfaction surveys, hospice and palliative care services have been slow to address the issue of user involvement.

Protection of the palliative care population is cited as to their exclusion from research (Gurwitz et al., and Larsen in Reid, 2009:30; de Raeve in Appleton, 2004:261). This protection could be construed as paternalism. It denies the participants the opportunity to be autonomous decision makers, and to be credited with the capacity to negotiate involvement for themselves. It has been suggested that such groups of individuals are often excluded from investigation without clear justification (Appleton, 2004). The exercising of self determination for terminally ill people and their family caregivers upholds one of the values of palliative care.

Palliative care research is fraught with a number of methodological difficulties, such as recruiting participants, high attrition rates, rapidly changing clinical situations, ethical dilemmas associated with research participation and gate-keeping behaviours exercised by professionals. (Aoun and Kristjanson, 2005:55)

These factors were evidenced in my own research project. Recruitment of family caregivers was problematic as already mentioned. The reasons can only be surmised; within the rapidly changing nature of terminal illness, participation in this research project required both caregiving and bereavement interviews to be undertaken. On several occasions potential participants made contact and wished to participate, but the terminally ill person died before the first interview was completed. I chose not to conduct the bereavement interview with anyone who had not participated in the caregiving interview. Time and focus constraints of the team members distributing information sheets may also have affected the uptake of research participants. Team members acknowledged that few information sheets were given out. Reasons for this are outside the scope of and time constraints of this particular study. This study did not seek interviews with terminally ill people. Caregivers themselves may not have pursued participation, if they saw their own role as unremarkable and if the emphasis of the care was on the terminally ill person.

Benefits of participation: Those participating in palliative care research do so for a variety of often altruistic reasons: to add to a body of palliative care knowledge even though they may not directly benefit or out of a sense of contribution, or the impulse to construct a narrative which assists caregivers in making meaning of the experience (Appleton, 2004). Motivation for people to participate in palliative care research/studies was related to altruism, gratitude and concerns about care, the need to have someone to talk to, the need for information or access to services.

The use of narrative “helps to make sense of the experience, ordering events into a more coherent structure that helps create meaning - an especially important dimension in the context of palliative and end-of-life care” (Rolls and Payne, 2008: 576). The exploration of the experience of caregiving in this study gives voice to this role and uncovers both salient and silent issues. The place of narrative is significant in creating and sustaining identity (Rolls and Payne 2008). Empowerment of individuals, such as caregivers, occurs when their perspective is attended to and conveyed in a forum outside that of the research interview. This is the genesis of increased political, community and organisational awareness of the importance of informal caregiving in palliative care.

While not an original aim of the study, participants indicated they had been given an opportunity to make a valuable contribution in the realm of palliative care, a sense of ‘giving something back’. The results of qualitative research conducted with family caregivers of terminally ill people gives practitioners a deep insight, a vehicle to improve practice, care delivery, education and training as well as offering a significant contribution to the reflective practice of palliative care professionals.

Considerations for the Researcher: The rapidly changing nature of someone with a terminal illness or the concurrent stressors of the caregiver constituted another ethical issue. To ensure that the terminally ill person was not at a stage of illness where it would be insensitive or inappropriate to approach caregivers, the decision to approach family caregivers for this study was designed so that it became a multi-disciplinary team decision.

The literature consulted on ethics in palliative care research emphasises the ethical challenges and practical difficulties (Agnew and Duffy, 2009; Appleton, 2004; Beresford et al., 2007; Dean and McClement, 2002; Gysels et al., 2008; Reid, 2009; Rolls and Payne, 2008). The importance of thorough, meticulous preparation in planning the written material, timing and content of interviews and the awareness that participants’ distress

may be present are all factors that guided my methodology and methods. The significance and clinical implications of palliative care research, whilst being a potential minefield in terms of ethics approval and ethical practice, will inform the provision of palliative care services. As noted in Chapter four, interviews were not conducted in the late afternoon or evening. This ensured the caregiver or bereaved person was not left isolated at a time of potential vulnerability. Participants are all to receive a bound copy of their own transcripts. It is my intention to phone each participant prior to posting to ensure adequate psychological preparation for each individual to receive this mail.

Caregiving and Bereavement

Grief as a response to an anticipated death colours one's world every day in a way that the grief to a sudden or unexpected death does not (Pearson, 2008). In the context of terminal illness, "witnessing dying can be a profoundly disturbing event for some carers, while for others it is both a privilege and a relief" (Payne and Rolls, 2009: 271). It is noted that for some, it may contain elements of both. The death of a terminally ill family member signals the transition from caregiver to bereaved person, the same people who provided the care are the ones who face bereavement. During the period of terminal illness there is a decrease or decline evident in the patient's functioning, appearance, mobility and capacity to interact with or perform every day activities. Grief is more complex due to these factors, in that grief is present as the caregiver witnesses these changes and this grief becomes part of their experience. Previous review of caregiving and bereavement in chapters two, three and five of this thesis demonstrates family caregiving is often more dynamic and complex than a simple one to one relationship would predict. While this complexity provides a framework for the following discussion, it is noted that the transition from caregiving to bereavement is not reflected in academic literature (Franco, 1996; Bernard and Guarnaccia, 2002; Duke, 1998;

Larkin, 2008 Payne and Rolls, 2009). Much of the literature consulted investigates the phenomenon of caregiving or the phenomenon of bereavement and a paucity of literature is available that focuses on the interface of the two.

A former carer is someone who does not necessarily identify themselves as a former carer but who has experienced an episode of caring in the past that ended with the death of the dependent. (Larkin 2008:4)

Bereavement support is of most benefit to individuals who recognise that they require support (Neimeyer, 2008 a; Payne and Rolls, 2009). Distinctions between 'normal' and 'abnormal' grief have traditionally been used to identify those 'at risk' in bereavement. These distinctions, using varied vocabulary such as pathological, complicated, prolonged, disordered, absent, or delayed grief are problematic as perceptions of grief are shaped by cultural, historic and social norms. Loss is universal, reaction to loss varies. Therefore it is difficult to identify that caregivers are any more likely to experience complex grief reactions than other bereaved people. That said there are specific factors in caring for a terminally ill person which will have an impact upon subsequent bereavement. The multidimensional nature of bereavement is informed by a constellation of variables: demographics, circumstances and situational factors influence the grieving process. Issues in bereavement are likely to vary with the nature of the relationship, the circumstances of the patient's death and any implications that the death may have on the survivor's wellbeing (Bernard and Guarnaccia, 2002). Caregiving experiences and the individual qualities of the caregiver can significantly alter the course of the bereavement (Allen et al., 2006). These experiences and qualities are constructed into categories that in her 1996 thesis Franco calls 'risk factors' for 'complicated bereavement disorder' or an 'unfavourable bereavement outcome' but Payne and Rolls refer to as 'well recognised attributes' in

which 'vulnerabilities' 'allow predictions to be made about which people are more likely to need more help'. These five categories will now be examined.

Characteristics of the bereaved: These include socio-demographic factors, personality, any previous psychiatric history and previous experience of losses and how these have been managed. The gendered nature of caregiving has been highlighted in feminist scholarship; the majority of those undertaking caregiving are women. Younger survivors and younger women especially had more immediate and enduring effects in adjusting to bereavement (Franco, 1996; Payne and Rolls, 2009), possibly due to young children, reduced financial security, and peers who lack age and experience to appropriately support. Other socio-economic factors that influence the bereavement of former caregivers relate to the resources available. Resourcing can refer to finances, with attendant increase or reduction in choice, or can refer to the coping strategies available to an individual resulting from intra psychic resilience or lack there-of.

Relationship to the deceased: Caregiving is predicated on existing relational ties, many caregivers in a terminal illness context are spouses or partners. Spousal relationships are traditionally viewed as more intimate and interdependent. The degree of attachment between the ill person and the caregiver is likely to impact on the course of bereavement: greater attachment leaves the bereaved person more vulnerable. Grief experiences differ with the specifics of the caregiving relationship (Bernard and Guarnaccia, 2002). Caregiving springs from close kinship or attachment, the caregiver may be the one with the most to lose from the other's death (Cantwell-Bartll, 2006). Greater dependency highlights the void when the caregiving role ceases: not only is the relationship lost, but the 'job' is lost also.

Nature and manner of the death: The circumstances and timeliness of the death are indicators of possible bereavement difficulties. Descriptors of a 'good death', such as excellent pain management, absence of distressing

physical symptoms or spiritual anguish are indicators that those in attendance may experience fewer bereavement difficulties. Death that is accompanied by distressing imagery may traumatise those witnessing it, leading to complexities in how grief is experienced. Stressful, difficult caregiving situations, including the care required at the time of death, predicts stressful, difficult bereavement (Allen, et al., 2006; Bernard and Guarnaccia, 2002). For family caregivers who provide care until death, the manner of the death itself will impact upon bereavement adjustment.

Family dynamics: The caregiving may be undertaken because the relationships are already more deeply involved, such as partner or spouse. The other relationships within the family are impacted on. Families are comprised of individuals, albeit, with a shared history and familial culture. Individuals respond to crises, loss and grief in varying ways. In a review Schultz et al., (in Allen, 2006) summarise the results of a number of studies, which indicated that caregiver and family issues significantly affect the adjustment to bereavement for family members. "I had to accept that death pulls us back into old patterns laid down, usually unspoken, unexamined, un-negotiated - silently - throughout childhood" (Maitland, 2008: 268). Issues resultant from familial interactions may lead to conflict, or past conflicts may re-emerge; new or existing alliance between family members may continue into bereavement, depriving family members of their natural support system.

Support: These are the networks that inoculate a caregiver or bereaved person against isolation or depression and that foster resilience. Support has been consistently shown to mitigate the stress of illness and bereavement (Bonanno, 2008; Duke, 1998) and emanates from a variety of sources including interpersonal relationships, things or places and ones own ideas and beliefs (Franco, 1996). Perceived and actual support may differ: it is the level of perceived support that remains significant (Franco, 1996; Payne, 2007; Payne Rolls, 2009). Social lives that may have experienced disruption during the caregiving period may be re-established in bereavement.

The 'colouring of one's world' referred to in the introduction to this section recognises that caregiving in a terminal illness context has some unique features. The profound emotional, interpersonal and contextual implications of anticipated death bring other issues into sharp relief. Uncertainty of prognosis, with limited time to adjust to physical, psychological and spiritual changes also has an impact on the caregiver who has to adapt repeatedly and to develop new skills. Hidden elements of caregiving such as planning ahead, anticipating and pre-empting physical deterioration or decline involve emotional labour while managing the overwhelming aspects of unbidden grief. Care at home requires a more rapid mobilisation of family resources to support the ill person, while simultaneously the family come to terms with their own identity and expectations. These emotional pressures are faced with the ominous threat of impending death: it may be the first time that the family or caregivers are exposed to dying. While recognising these factors, it is also noted that caregivers derive a sense of value and report high feelings of satisfaction. Care of an ill family member may strengthen advocacy skills, confidence and knowledge. The family unit who faces the loss may experience increased closeness. Meaning reconstruction in the face of life, mortality and death reorients past, present and future. If there is no future to be created, the present becomes more present. Families have the opportunity, whether utilised or not, to express what may have been previously unsaid. The dying and death of someone close to us is one of the hardest times of transition (Hera, 1995).

Clinical Implications

The findings of this study reiterate the need to acknowledge and listen to the needs and experience of those family members who care for someone with a terminal illness. The voice of service users or consumers of any service is vital to ensure that service delivery is a match with users. Given that the phenomenological methodology framing this study is concerned with description rather than prescription, the clinical implications from this

study alone need to be approached with caution. As discussed in the chapter on methodology, the examination of the data was concerned with the experience of caregiving and the experience of subsequent bereavement and cannot be perceived as a causal connection.

In a bio-medical discourse, the focus of care is primarily on the terminally ill person; that focus is often on symptomology, medication, and patient self-determination. The precepts of palliative care are to support the family as a unit of care. At times the wishes of the ill person and the capacity of the caregiver are not synonymous. Family caregivers, as has been demonstrated, are pivotal to hospice at home care.

Increased awareness of the role and significance of the family caregiver is vital to ensure good palliative care practice. The experiences of the caregiver must surely have an impact on bereavement. The study suggests that the events and care surrounding the death of the terminally ill person have implications in bereavement suggests that caregivers also need to be attended to, in order to support healthy bereavement.

This study increases the visibility and role of family caregivers. The findings of this study have implications for clinical social workers who provide direct care to clients and family, as well as to those who administer programmes, develop policy, train social workers and conduct research, to be more aware of the impact of the caregiving role on those who undertake it.

The provision of bereavement support groups are a common feature of hospice care. Increased awareness of the support needs and experience of caregivers may lead to caregiver support groups. I suggest that these be facilitated by social workers and include both informational and process components. Recounting the narrative of the caregivers has been demonstrated as therapeutic for these four caregivers involved in this

study. The value of a support group may be generalisable to other caregivers.

Limitations of the Study

This study was based on a small group of caregivers in the capital city and its region of New Zealand. All the participants were caring for a family member with a diagnosed terminal illness. As such, a small sample size, the reasons for difficulties in recruitment, and the representation of this group of caregivers makes generalising from this study alone problematic.

Future Research

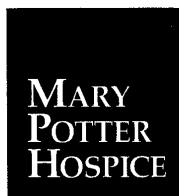
Carers New Zealand is establishing a forum that fosters research into caregiving. Specific research on carers in a palliative care setting is recommended. This research would need to canvass what such carers identify as helpful to them. Funding for palliative care research is likely to continue to be a hurdle. Increased acceptance of the voice of all service users is strongly endorsed.

Concluding statement

From the general literature on caregiving, it is well established that family caregiving has serious negative affects on physical and mental health. Providing care for a terminally ill family member adds the construct of privilege to the previous construct of burden. How family members respond to the multi-faceted demands of caregiving depends on a number of factors. This study has examined the experience of four family caregivers and concludes that the privilege of caregiving at life's end mitigates the burden. The aim of this project was to find out more from the experience of caregivers, to give them a voice, empower caregivers and raise awareness of caregiving. During the research process and data analysis, I became aware that the research question had cause and effect as its primary focus. As discussed earlier the research is an examination of

the experience of caregiving for a terminally ill family member and the experience and process of subsequent bereavement. Parallel to my own increased awareness of the significance of family caregivers in palliative care, is an increase in the political and academic visibility of issues relating to caregiving in a terminal illness context.

Home palliative care would be impossible for many people without the support of family caregivers. This caregiving experience has implications for the bereavement experience of these caregivers.



making the most of life

21 May 2008

Central Regional Ethics Committee
C/- Ministry of Health
2nd Floor, 1-3 The Terrace
Wellington

To whom it may concern

Re: Virginia Lee- Masters Thesis

"In what ways does the experience of caregiving for a terminally ill family member impact the experience of bereavement"

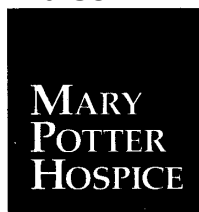
This is to confirm on behalf of the Mary Potter Hospice that we support Ms Lee in the research she is undertaking for her Masters degree. Please contact me if you require any further information

Kind regards,

Yours sincerely

A handwritten signature in black ink, appearing to read "B Ensor".

Dr Brian Ensor
Director of Palliative Care



making the most of life

Central Ethics Committee
C/-Ministry of Health
2nd floor, 1-3 The Terrace

To whom it may concern,

Virginia Lee has consulted with myself in regard to her research paper titled 'In what ways does the experience of care giving for the terminally ill family member impact upon the experience of bereavement?' and I endorse her ability to practice cultural safety and awareness in all aspects of her profession. Virginia Lee demonstrates a sound knowledge of working within the principles of the Treaty of Waitangi, as a practitioner at Mary Potter Hospice. She possesses a sound knowledge of tikanga Maori and has an appreciation of cultural issues that affect Maori. I have no hesitation in recommending Virginia to undertake this thesis.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Katherine Reweti".

Katherine Reweti
Maori liaison Palliative-Care
Mary Potter Hospice
Wellington



Massey University

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

Te Kura Pūkenga Tangata

Research participant information sheet

SCHOOL OF HEALTH
AND SOCIAL SERVICES
Private Bag 11 222
Palmerston North 4442
New Zealand
T 64 6 356 9099
F 64 6 350 5668

“In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?”

Researcher: Virginia Lee

Supervisors: Dr Mary Nash, Senior Lecturer Massey University, tel 801 5799 ext 2827 and Dr Martin J. Sullivan, Senior Lecturer Massey University

Research Outline:

Kia ora and Hello

I am currently doing some research on the experience of caregiving for a terminally ill family member and the experience of bereavement. I wish to see what meanings people such as you make of these experiences.

The findings from the study will be of interest to social workers, counsellors and other hospice staff who wish to extend their understandings of the role of the caregiver and the experience of bereavement.

I am undertaking this as part of a Masters of Social Work from Massey University, Palmerston North. I am, however, based in Wellington.

How you can help:

I am looking for up to 10 participants who have a terminally ill family/whanau member who is part of the Mary Potter Hospice service in the Wellington Team. I would like to interview you while you are in your caregiving role and then again at a later date when you are bereaved.

Each interview will be about an hour, and I will ask you to describe your experiences, your thoughts and impressions about being a caregiver. The later interview will be done in the same way, asking you to describe your experiences and how caregiving has shaped you and your bereavement.

Anonymity and Confidentiality:

Each interview will be taped and later transcribed into a written form. The transcript of the interview will be returned to you to verify and review. No material which could personally identify you will be used in any reports of this study

Your involvement is completely voluntary. The person for whom you are caring will be part of the Mary Potter Hospice service whether you are interviewed by me or not. If you decide to take part, you may withdraw at any time if you wish.

How to participate:

If you are interested in being part of this study please contact me by:

- Tel 938- 2748 my home phone number. Please feel free to leave a message
- E-mail rllee@clear.net.nz write 'research' in the subject line
- Text or cell ph 021 1648 988

I will then contact you by phone or e-mail.

Thank you for considering this request

Virginia Lee



Te Kura
Pūkenga
Tangata

Caregiving Interview

1. How were you told of the diagnosis? – What was your experience of hearing this?
2. How has the caregiving role evolved for you?
3. What has been your experience of coping with this role as caregiver, including your own feelings about what this experience has been like for you?
4. Did you have any pre-conceived ideas or past experience of caregiving?
5. If so, have your ideas and experiences changed for you? Are they different or are they the same?
6. What supports you or sustains you through this experience of caregiving?

Bereavement Interview

1. Can you tell me about your last few days together?
2. What have the last few months been like?
3. As you look back with hindsight, is there anything you now realise that could have made a difference for you?
4. Is there anything else that you realise about your caregiving role that you see in retrospect?
5. Tell me about how the role as caregiver for might be colouring things for you now.
6. What supports you or sustains you at this point?
7. Is there anything else that you would like to mention?

Project: *In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?*

I (name)

agree to transcribe the tapes provided to me accurately.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature.....

Date.....

Consent Form for Participant

Project: **In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?**

I have read the introductory letter/information sheet for this study and have had the details explained to me. My questions have been answered and I understand that further questions that may arise throughout the project will be answered as best they can by the researcher.

I understand that I am free to withdraw from the study at any time up until the data analysis is complete and I am entitled not to answer any question in the study.

The person for whom I am caring will be part of the Mary Potter Hospice service regardless of my participation or withdrawal. I understand that should I withdraw during my bereavement, I will still receive the bereavement services offered by Mary Potter Hospice.

Confidentiality is a foundation for this project and any information I give is with the clear understanding the information given is confidential. I understand that there will be no identifying details in the interviews once transcribed.

I do / do not consent to have taped/digitally recorded interviews

I do /do not consent to have my taped interviews/ digitally recordings transcribed by a transcriber who has signed a confidentiality agreement

I wish /do not wish for the tapes / digitally recordings of my interviews to be held in an official archive for 5 years after which the tape/ digitally record will be destroyed

I wish /do not wish for the tapes/ digitally recordings of my interviews to be returned to me once the study is completed.

I participate in this study under the terms and conditions set out in the introductory letter

I wish /do not wish for a transcribed copy of my interview to be given to me.

Signed _____

Name _____

Date _____

Sample Letter of Thanks to Participant

Appendix 8

Sample of hand-written letter sent to each participant in the days following the first interview.

Dear.....,

Six days after your interview, I remain profoundly thankful to you for participating and sharing your story with me (and the tape machine).

Thank you for your courage and time in doing this.

I shall contact you when I have your words transcribed for you.

Kind Regards

Virginia Lee



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

13 August 2008

Ms Virginia Lee
Mary Potter Hospice
PO Box 7442
Wellington South

Dear Virginia

In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?

Investigator: Ms Virginia Lee

**Approved Site: Mary Potter Hospice
CEN/08/06/028**

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

Approved Documents

- Participant information sheet Appendix 3, Version 2
- Consent form for participant Appendix 7
- Care giving Interview Appendix 4
- Semi-structured interview schedule Appendix 5
- Confidentiality agreement for transcriber Appendix 6

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until 28 February 2010. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in August **2009**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

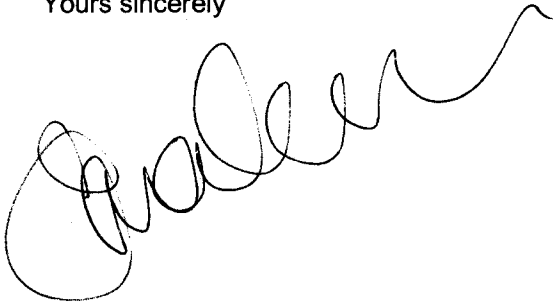
Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study 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. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Emalene Pearson', written in a cursive style.

Emalene Pearson
Multi-region Ethics Committee Administrator

Email: emalene_pearson@moh.govt.nz

Approval from Ethics Committee for Locality Extension Appendix 10



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington

Phone: (04) 496 2405

Fax: (04) 496 2191

Email: central_ethicscommittee@moh.govt.nz

20 November 2008

Ms Virginia Lee
Mary Potter Hospice
PO Box 7442
Wellington South

Dear Virginia

CEN/08/06/028

In what ways does the experience of caregiving for a terminally ill family member affect the experience and process of bereavement?

Ms Virginia Lee, Mary Potter Hospice


Documents received:

Locality assessment by B Endor, Director of Palliative Care, Kapiti Team, Mary Potter Hospice.

Thank you for the request to add the Kapiti Team of the Mary Potter Hospice site to the above approved application. The addition of this site was considered by the Chairperson of the Central Regional Ethics Committee under delegated authority on 5 November 2008 and approved.

Please quote the above ethics committee reference number in all correspondence.

Yours sincerely



Sonia Scott
Central Regional Ethics Committee Administrator

Email: sonia_scott@moh.govt.nz

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