

Palliative Care in Context: An Ethnographic Account of the Journey From Diagnosis to the End of Life

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Abstract

This study of palliative care in context was conducted in a major New Zealand city and examines the journeys of eight people with a life-threatening illness and the journeys of 83 members of their families.

The material presented here was gathered over a period of three-and-a-half years by utilising an ethnographic methodology. The ethnographic research design was used to collect data from observations and informal discussions, and supplemented by semi-structured interviews, in a variety of settings. The research was conducted in conjunction with a community palliative care service. Participants were people who were referred to the service, and their family members.

The thesis begins by locating culture as a central element or lens. The history and development of palliative care services, together with current issues in end-of-life care, contribute to the contextual background of the thesis. I also consider the role of social work in end-of-life care, and explore some of the current issues facing this social service.

The theoretical underpinnings of the thesis are informed by the ecological perspective combined with psychosocial theories of loss and grief. The use of this combined theoretical approach provides a framework for the task at hand: to understand the experiences of individuals and families in their journey from diagnosis to the end of life. Drawing on a broad social systems theory, in conjunction with an ethnographic methodology and grounded theory analysis, contributes to the development of research which firmly takes

culture into account. An ethnographic methodology openly positions the researcher “self” as a source of information and reflection. There is no attempt to maintain a neutral stance as the research relationship deepens.

The information gathered from the years spent in the field is presented in chronological fashion and divided into four primary topic areas: a narrative exploration of diagnosis, the changing landscape that participants encounter, the embodiment of new places and spaces, and finally, the journey’s end. The themes from the four topic areas contribute to the development of the two core categories “time and place” and “preparedness for death”. A schematic representation of the paths participants took is provided in the discussion of the core categories. These paths are considered in light of the topics raised throughout the thesis. Lastly, the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001) is drawn on to aid the discussion of issues arising from the research and the implications for practice in this field.

The intention of this thesis is to provide information about the unique journey that each participant with a terminal diagnosis undertook, and to highlight the barriers and obstacles each faced. This was done whilst considering the role that cultural identity plays in the journey and at the end of life. The participants’ cultural background and social circumstances, in conjunction with the influences of the health system, contributed to the decisions they made throughout this journey. How well prepared they were for the end of life can be regarded as the result of interactions between the two systems: the socio-cultural system in which the individuals are embedded and the health system.

Preface

To be an ethnographer is no easy task, but to be one's own ethnographer is even more challenging.

I began the fieldwork component of my research in the autumn of 2005. My intention had been to spend one year in the field documenting the journey of a group of terminally ill research participants. Difficulties in recruitment of participants resulted in participants still being recruited in late 2006. Walking alongside the participants, I came to realise that once they had let me into their lives, and their process of dying, I could not walk away from them during the journey. I made the commitment to stay the distance, and I was, therefore, involved with all of them at the time of their deaths. Having made this commitment, the challenge was to manage the ongoing data collection alongside data analysis. (This process is discussed further in Chapter Four, section 4.5). As notes were transcribed they were added to the ongoing analysis and so the thesis began to evolve. The last participant died in the spring of 2008, three-and-a-half years after I had begun the fieldwork.

Having spent so much time in the field I felt I had developed a fairly intimate understanding of the processes that the participants had been through, from diagnosis to death. I had an immense amount of empathy for all of them and really felt their sadness as they spoke of their diagnosis and attempted to come to terms with the information that they had a life-threatening illness. From spending so much time with the participants and paying attention to the intimate details of their experiences, I felt like I knew in my heart what this had been like for each of them, I felt like I was part of their journey and their process. As I

wrote each chapter of the thesis, I wove my research experiences into the analysis. I developed my story as the ethnographer alongside that of the participants and made connections between the two parallel processes. I began to understand that telling the participants' stories involved telling the story of my journey alongside them. I came to realise that the culmination of their life, was the culmination of my experiences with them. I had travelled a multiple-layered journey with these participants and my experiences were indeed one of the findings. As a result of this understanding, early drafts of the thesis contained many instances where I discussed the researcher "self", my perspectives, insights and experiences. I did not know at the time that I was about to become my own ethnographer, and that this experience would significantly alter my thoughts about the parallel nature of my journey alongside the participants.

In the spring of 2008 as my last participant was dying, I was diagnosed with invasive breast cancer. In shock, and desperately trying to come to terms with my diagnosis, I began to use the tools I had developed throughout the fieldwork, that of documenting the journey. I began to make field-notes of my experiences as I traversed the now familiar landscape of oncology services. I had requested and was granted a one year suspension from study. During that year I underwent surgery and treatment. Having spent three-and-a-half years in the field with the research participants I had been introduced to many of the oncology doctors and nurses. It was very strange, therefore, to suddenly become "the patient" in a system where I had been recently known as a professional.

As I went through the process of diagnosis and treatment, I knew that there would need to be a place for this experience in my thesis, and that somehow my experience would provide me with even deeper insight into the participants' experiences. The very personal experience of diagnosis with cancer led to a significant shift in my thoughts about some of the topics covered in the thesis. In particular, I began to think about the level of involvement I had with the research participants. During the research, I felt like I had developed an in-depth understanding of what it meant for the participants to be diagnosed with cancer. After I was diagnosed, I realised that no-one can really understand what it means to hear those words, "you have cancer", unless you have been given that news. In my field-notes the day after I was diagnosed I wrote:

I'm aware that I feel as if I am moving through silence, the whole world feels like it is shut out from this experience. I feel a sense of vulnerability around people and I notice I avoid eye contact. I feel as if everyone who looks at me knows I have cancer. I feel like I am removed from the world that I am moving in. I do the work I have to do in between thinking about how to tell my family. I think about how I am going to tell them and how they will feel. I feel that I am inflicting this cancer on them, that somehow they will also be inextricably altered by this news. This will now be about them; this will be something that is happening to them, even though the cancer is only in my body. This will affect their lives, decisions, thoughts, and relationships, I have seen this many times before. I cannot protect them from this news, I can only break it to them gently, with information

not just emotion. I can tell them how optimistic I am about living a long time with this cancer as so many other women are doing. I think of how this was for my research participants, and I am grateful that I can at least tell my family that I am not going to die.

Being diagnosed with cancer was an incredibly solitary experience and although people supported me in many different ways, they could not walk the journey for me. Following my diagnosis I often reflected on the stories participants had told me. I realised that I was not as much a part of the process as I thought I had been. I had seen myself as firmly located inside the research experience and yet this new insight showed me that I had always stood outside of the participants' experiences.

When I returned to the thesis after this period of absence, I sat down and read it from beginning to end. I realised that many of my thoughts and understandings had been altered by my own experience of cancer. I discussed my thoughts with my senior supervisor and we came to a compromise. I would leave my thoughts about the parallel process I took with the participants in the thesis, but I would delete details about my experiences that no longer felt appropriate or true to me now. We also decided that as time was limited to complete the thesis, including my new insight into every chapter was impractical, therefore, I would write this preface as a way of positioning my own experiences within the thesis. There have been a few instances in the re-writing process where I have briefly mentioned my experiences in the body of the thesis, but on the whole, my story is contained within this preface.

Chapter One

The Journey Begins

... we learn about having a terminal illness and our naïveté about life as we know it ends. Dying becomes part of our reality. We can't go back. We move through those transitions and changes to a new way of being, a new understanding of ourselves, of our community, and perhaps even of the world. (Kuhl, 2002. p. 139)

1.1 Introduction

So the journey begins; a journey through familiar and unfamiliar landscapes of palliative care to the twilight zone at the end of life. Although I am walking this journey to fulfil the requirements of doctoral study, I have embarked upon it at a level of deep personal enquiry. In the first section of this chapter, I provide an outline of my personal experiences of death and dying which led me to the topic areas of: cultural identity, place, and the end of life. I then present the aims of the research and discuss the significance and relevance of the thesis topic. In order to set a context for the thesis, I provide a brief history of the development of end-of-life care services and explain current debates within those services. Finally, I provide an overview of the structure of the thesis.

1.2 Conception

My choice to embark upon a PhD study in palliative care has in part arisen from my own narratives that are grounded in a multitude of experiences of death and dying. The knowledge I have gained from my own experiences with death and dying inevitably and appropriately inform the research process. Kohn and McKechnie (1999a) argue that the

“detailed reflexive observation” of people who are in the position of caring for someone who is dying can add a degree of knowledge to their research by drawing upon this experience. Okely (1999) takes this argument a step further by suggesting that research methods, such as ethnography, which attempt to provide an “insider’s” perspective may sometimes fail to do so as the researcher can still be located outside the experiences of the research participants. They may, in fact, remain estranged from the experiences and not gain a deep and profound understanding of the intimate issues at hand. As an example of the researcher/personal carer experience, Okely (1999) draws on her own experiences of caring for her mother until her death. In her article “Love, Care and Diagnosis”, she explains the importance of bringing our own anecdotal experiences into our discussions. She also discusses the “flawed nature of expert’s knowledge” (p. 20), when the researcher denies knowledge gained from lived experience and the wealth of information that can be gained from listening to “grounded indigenous knowledge based on practice [and personal experience] . . . and ethnographic knowledge grounded in participant observation” (Okely, 1999, pp. 21-22).

Each of my experiences around death and dying has left me with certain questions or thoughts which have informed this PhD enquiry into palliative care and culture. I am a first generation New Zealander, born to Scottish immigrant parents, who both originated from Glasgow. My parents came to New Zealand on the last sailing of the Captain Cook on the 17th June to 24th July 1958. They chose the city we live in as their “new home” simply because they had relatives to stay with. The main influences on me as a child were: religion, my father’s love of the outdoors, my mother’s solid and loving presence in every

facet of my life, my extended family network, friends and neighbours, and a grand mixture of informally adopted Scottish, Irish, and English relatives.

As a child growing up, I was confronted by death at an early age as two girls I attended primary and secondary school with both died from different causes. As a young mother, I was hospitalised for a period of months and became great friends with a woman whose baby died at birth. My friend had to decide whether and when to turn off her baby's life support. It was an incredibly difficult decision and a very sad experience, as she did turn it off when he was a week old. I experienced the death of my mother-in-law and my grandmother in the early 1980s, and I found that their deaths seemed somehow acceptable as they had both lived a "good long life". Although I felt sad about their deaths, I felt my grief was easier to process than it had been when my friend's baby died. I soon experienced the death of another friend's baby from cot death, and I felt helpless and sad about this seemingly pointless death.

These deaths were followed closely by the death of my maternal grandmother and, two years later, my adopted grandmother. At this point, in the early to mid-1980s, my own life underwent some drastic changes. This journey led me to study at Polytechnic where I developed a close relationship with an older woman who became my teacher, my friend, my confidant, my mentor, and my role model. Several years later (1989), after I had supported her through an intense and exhausting battle with cancer, she died.

Soon after my friend's death, my father was diagnosed with cancer, and it was this experience that clarified my own course of action for the future. My father and mother taught me about the role of culture in death and dying, and the important functions that cultural beliefs and practices play in our lives and deaths. I learnt about my ability to "let go" of someone I loved and to give him permission to "let go" of all of us. The afternoon my father was diagnosed, he was told he had inoperable abdominal cancer and died within seven months. Despite the finality of the verdict, he appeared to have a profound acceptance of his prognosis. He had a deep faith and was involved in our local Catholic church. This faith held him through the pain of his illness. Our family united and supported one another as they never had before. My son sat with his granddad every day after school, they were as close as any two beings could be.

Apart from one brief time in hospice, my mother looked after Dad at home until the day before his death, when he was admitted to hospital. Our family gathered and by early the next day, Dad had slipped into a semi-conscious state. For hours we talked to him and told him that he could leave us now. We told him stories about who was in the room, what they were doing, how much they loved him, and what an amazing father he had been. He smiled a lot while we talked, and at about a quarter to 12 that night, he opened his eyes and said his final words goodbye. We all held hands in a circle around his bed and prayed his favourite prayer, as he slipped quietly from the world (8th June, 1993).

During the time of his illness, Dad talked a lot about home (Scotland). His sisters from Scotland visited New Zealand so the house was often full of Scottish people. Dad helped us

plan his funeral and he was very clear that we needed to hold a wake and that his body should not be left alone. This embracing of his cultural roots was vital to his clarifying who he was and where he was from, and naming his ancestors who were awaiting his arrival in heaven. Being a Scottish Catholic was a significant part of his identity. The church played a central role in his living with dying, and the symbols of catholicism were evident in Dad's death and dying process (Catholic ritual, rosary beads, Catholic icons, last rites, and so on). There was also the need for us to stay with Dad at the hospital, as he wanted his whole family around him at the time of his death. This included extended family who were not blood relatives but were vital parts of our wider New Zealand family. As immigrants we had few blood relatives in New Zealand. We took up a lot of space at the hospital and there was the issue of where we would physically locate ourselves as a family until Dad's death. We were given the waiting room and promptly moved in. We all stayed (children and adults) until well after his death. The staff were most accommodating, understanding, and the charge nurse, who was also Scottish, was a wonderful support.

The same week as my father died, my foster brother Tommy died of AIDS. During his illness, Tommy and I wrote to each other, and he wanted to talk a lot about our family and his place in it. He also turned to religion as a form of solace during his illness. Tommy designed his own funeral service before his death, and he drew a lot on the role of family, gay cultural symbols, and the experiences that he had as a gay man dying of AIDS.

Not long after my father's death, I experienced the deaths of both of my maternal aunts. They died within four years of each other, one from emphysema, and one from a malignant

brain tumour. They were both still quite young, and I was struck by how similar the way they died was to the way they had lived. Kubler-Ross (1969) says that we die in character, and I fully agree. My father loved an audience, and he waited until every single last member of our “family” was there until he died. My oldest aunt was a very nervous and uptight person and it always struck me that she was afraid of life. She was also very afraid in the hospital before she died, and although we tried everything to calm her down, she died distressed and anxious. My youngest aunt, however, was the total opposite. She had always been the quietest member of my mother’s family, and sitting by her bed when she died was like watching an angel slip away.

From these experiences, my father’s death in particular, it became fairly clear to me that I wanted to work in this field. I decided to go to university and gain qualifications for the job. My enquiries led me towards undertaking a double degree in psychology and social work, with a view towards completing a Masters or PhD in the area of end-of-life care. My intention was to eventually work with people who are dying and their families in an agency that can provide support to all the members of the family/extended family.

1.2.1 Professional development

In the third to fourth professional years of the Bachelor of Social Work (Hons) (2000-2001) I was studying at the Department of Social Work, University of Canterbury, and with the help of the Department, I arranged a placement in an end-of-life care facility, The Centre for Attitudinal Healing, in San Francisco. I spent three months in the United States and worked at this centre. During that time, I lived with a long-term friend and helped her to

care for her mother who had Alzheimer's disease. I had spent time with my friend's mother on previous visits and had cared for her on numerous occasions. We grew to be very close, and had a wonderful last summer together before her death the following winter. During this time, two of my clients at the Centre also died after long, exhausting battles with cancer. I began to learn about the differences and the similarities between caring for people with a terminal illness in a professional sense and in a personal situation. I continued my work at the Centre for Attitudinal Healing in a voluntary capacity after the completion of my placement and learnt as much as I could about the different journeys people take when facing their own death or the death of a loved one.

By this time, I had so many personal and professional experiences of death and dying, I became interested in how the people I had known had dealt with their impending death or their bereavement in quite different ways. I began to read about indigenous cultural understandings and meanings of death and dying. The understandings that I gained from the beliefs around death and dying in other cultures provided me with a way of deriving "meaning" from the deaths I had experienced, especially that of my dearest friend and mentor. I also began to wonder why I had never been told, when growing up, how to deal with death; why I had no way of understanding it, and no way of locating it in my life experiences. All I had were some fairly frightening ideas about heaven and hell, and some fairly dubious ideas about who would go where. I wanted to know more about the way death and dying is managed in our society and how people with a life-threatening illness draw on their own culture to assist them in coming to terms with dying. It was the accumulation of these experiences that assisted me in developing my topic of enquiry for

this thesis; a topic that necessitated the use of a sensitive research methodology which would allow me to record in rich detail the journey from diagnosis to the end of life.

1.3 Aims and Significance of Study

The *New Zealand Palliative Care Strategy*, published by the Ministry of Health (MOH) in 2001, establishes clear goals for Aotearoa New Zealand's palliative care services. At a national level, therefore, the current study is particularly timely, as it can provide a medium whereby an understanding of the experiences of families who have been involved with palliative care services can be accessed.

The main aims of the research are: *to understand how individuals and families make meaning from the experience of being referred to palliative care services; to explore how shared understandings are drawn on by an individual and his or her family to make meaning of the process of engagement with palliative care services; and to explore how the individual and his or her family understand their decisions about end-of-life care.* These aims involve investigating the relationship between individuals with a life-threatening illness and their families (or significant others) and palliative care services. By utilising an ethnographic research methodology, this research considers whether, and how, people draw on aspects of culture in aiding them in the journey towards death, and how this cultural meaning making is aided or impeded by palliative care systems.

The intent of the research is to contribute to the knowledge and understanding about the experiences of people with a terminal illness and their families at the palliative care

interface. This understanding draws on the meaning and expression of culture utilised by participants in both their interactions with palliative care team members, and their understanding of death and dying. In so doing, this will make a significant contribution to knowledge in the areas of ethnographic research, palliative care, and cultural studies in Aotearoa New Zealand. Knowledge generated from the research will also make a substantive and original contribution to the international understanding of individuals' and their families' experiences and understandings of palliative care.

1.4 Relevance of Thesis Topic

There are an overwhelming number of books and articles about death and dying in an extensive range of cultures around the globe, and there are literally thousands of books and articles on spiritual aspects and beliefs about death and dying. Yet there are very few that examine the process of experiencing death and dying from the perspective of the family involved in the process and the terminally-ill family member. There is an increasing amount of attention being paid to family care-givers at all stages of the life course (Kissane & Blotch, 2002; Phillips, Bernard, Phillipson, & Ogg, 2000; Wright, 2000), and a growing body of research on palliative care that documents staff perspectives, understandings, and experiences with individuals and families receiving palliative care services (Carter, McKinley, Scott, Wise, & McCleod, 2002; Mitchell & Owens, 2003; Ross & Cornbleet, 2003; von Gunten, 2002). However, very little of this research explores individual and family experiences of palliative care services in the home or within a residential hospice (Smith, 1982), although this has been done in relation to euthanasia (Swarte, van der Lee, van der Bom, van den Bout, & Heintz, 2003). Some studies have, however, explored

certain aspects of patients' and their families' experiences with palliative care (Kirk, Kirk, & Kristjanson, 2004; Murray, Grant, Grant, & Kendall, 2005).

Kirk et al. (2004) carried out a qualitative study using semi-structured interviews with 72 patients and their families, to explore patients' and their families' communication needs. In another study using qualitative interviews, Murray, Grant et al. (2005) compared the experiences, needs, and use of palliative care services of patients and families involved in a longitudinal study in Scotland with the needs of patients and families involved in a cross-sectional study in Kenya.

Furthermore, as Lawton (2000) states, there has been very little study of how people understand themselves in everyday life, let alone during traumatic events such as illness, death, and bereavement. The majority of available research focuses on cancer-related deaths as opposed to death in old age and non-malignant or degenerative disease. Drawing on biographical or autobiographical accounts of illness, death, and dying can assist in gaining more understanding of how people deal with traumatic events (see Okely, 1999, and Houghton, 2003). The current study explores individuals' and their families' understandings of death and dying, as well as contributing to the development of research-based literature on palliative care; special attention is paid to the diversity of cultural expressions and understandings that arise in end-of-life care.

1.4.1 Taking culture into account

Studies that do consider the individuals' and families' experiences have, however, neglected to consider what aspects of an individual's cultural identity aid or impede them in coming to terms with their own death or that of a close family member. In order to understand the role that a person's or family's cultural identity plays when a family member is dying, we need to first understand what is meant by the term "cultural identity". Each society and each person within society has a unique cultural identity that sets them apart from others within that society or sets one society apart from another. Clarification of this term involves setting "cultural identity" in an appropriate historical context and then tracking the influences and alterations in our beliefs about it over time. The concept of culture is explained by Alasuutari (1995, p. 25) as being a kind of "collective subjectivity, that is, a way of life or outlook adopted by a community or social class".

Although studies on death and dying that purport to take culture into account do exist, they refer to culture largely in terms of ethnicity (Al-Krenawi & Graham, 2001; Graham, 2002; Murray, Grant et al., 2005; Seale, Addington-Hall, & McCarthy, 1997), not in the wider context that is used in the current study. In the 1980s, Kalish and Reynolds (1981) argued that although more people were talking about death and dying, the research on which these conversations were based had advanced very little over the previous few decades (1960s-1980s). They explained that the most of the information about death and dying was based on religious, spiritual, and transpersonal notions of death, as well as discussions on caring. Kalish and Reynolds not only looked at individual differences in the need for disclosure of information about the patient's prognosis, but also at differences across cultures. The lack

of research on people dying in developing countries has been noted by Seale (2000), who argues that death in younger age groups and cultural differences in the provision of care for older persons have not been well documented either. One study that does look at the issues for people dying in developing and developed countries, as noted earlier, was carried out by Murray, Grant et al. (2005).

Murray, Grant et al. (2005) found that the needs of people with cancer who were dying in developing countries were quite different from the needs of people dying in developed countries. Whereas people in developed countries had access to health services that provided pain and symptom control, people in developing countries often did not and, therefore, died in considerable pain. The need for emotional and spiritual support was well met in the developing country that was studied, Kenya, but was not so well met in the developed country that was studied, Scotland.

The current study provides valuable empirical data about individuals' and families' responses to the loss of a family member, whilst considering the more broadly defined cultural context and the implications of this loss. It also explores the content, process, and context of observations, narratives, informal interviews, and semi-structured interviews, to provide a valuable body of empirical data. The study is being conducted at a time when information about palliative care in Aotearoa New Zealand is required and could, therefore, be well utilised. The development of palliative care nationally and internationally is an interesting topic in its own right. I now provide a brief history of the development of "palliative care". This is intended to be a brief, contextualising overview, provided at this

point in the introduction in order to clarify the concerns currently topical and explain the terminology used in this field. The thesis is not primarily a history of palliative care.

1.5 History of Hospice Care, Hospital Care, and the Palliative Care Philosophy

With the advancement of the 20th century, death was removed from the hands of family members in their own homes, and put into the hands of professionals in institutions such as nursing homes and hospitals. The effect of this over time was an ever-widening gap between the living and the dying. Death was often viewed as something to be conquered or managed by medical intervention (Callahan, 1995), rather than a natural event. People who were dying often became isolated in the hospital environment where they were either avoided (Fordham & Dowrick, 1999), received minimal attention (Pincombe, Brown, & McCutcheon, 2003), inadequate care (Carter et al., 2002), were viewed as failures, or ignored and shunned (Lamerton, 1973). Health professionals concerned about the inadequate treatment of the dying provided the impetus for the development of hospice and palliative care (Bruera & Lawlor, 1998; Ellershaw & Ward, 2003). The broadening area of practice that drew on hospice principles was first called “palliative care” by Balfour Mount in 1974 (Clark, 2002); this term has been in fairly common use since that time. Palliative care is defined in the *New Zealand Palliative Care Strategy* (MOH, 2001) as follows:

Palliative care is 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 multidisciplinary team that works with

the person who is dying and their family/whanau. Palliative care as described by Field and Cassels:

- Affirms life and regards dying as a normal process
- Aims neither to hasten nor to postpone death
- Aims to provide relief from distressing symptoms
- Integrates physical (tinana), social (whanau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whanau attain an acceptable quality of life
- Offers help to the family/whanau/carers during the person's illness and their bereavement. (as cited in Hawthorne & Yurkovich, 2003, p. 2)

Field and Cassel also provide a definition of palliative care as an ideology that “seeks to prevent, relieve, reduce or soothe the symptoms of disease without effecting a cure” (as cited in Hawthorne & Yurkovich, 2003, p. 261). Field and Cassel suggest that one of the primary tools for achieving this objective is focusing on the development of a relationship. Relationship is the basic dimension by which people make meaning from their life experiences, by which life is given purpose, and by which one's existence is confirmed (Hawthorne & Yurkovich, 2003).

1.5.1 Hospice care

The word “hospice” is derived from the Latin word “hospes” which means to host guests or strangers, and was used in early Western civilisation to describe a place of shelter for sick or weary travellers (Brattleboro Area Hospice [BAH], n.d.) The name “hospice” was first used to describe care of the dying by “Mme Jeanne Garnier who founded the Dames de Calaire in Lyon, France, in 1842” (Amitabha Hospice Service [AHS], n.d.a). It was then re-introduced by Mother Mary Aikenhead who founded the Irish Sisters of Charity in the 1800s (Lamerton, 1973). The Irish Sisters of Charity opened Our Lady's Hospice in Dublin in

1879, followed by St Joseph's Hospice in London in 1905 (AHS, n.d.a). The Sisters of Charity and other Christian groups ran homes for the care of the dying for about 60 years before the development of the modern hospice movement (Lamerton, 1973).

1.5.2 Palliative care philosophy

During the 1950s, there was increasing awareness of the need for more attention to the care of the dying. According to Clark (2002), concern about the care of the dying was gaining attention during the 1950s in America and Britain. He outlines four particularly relevant innovations that aided the move from a medical approach to dying, to a more person-centred approach, which is embraced by today's palliative care philosophy. Firstly, literature on dying began to focus on systematic observation and research-based information as opposed to anecdotal stories. This had the effect of promoting more humane approaches to terminal care and countering arguments for euthanasia. Secondly, new ideas began to surface about dying that encompassed notions of openness, meaning, and dignity. Thirdly, instead of seeing the move to palliative care as the "end" of doctor's care, and the end of hope for the ill person, this shift was re-conceptualised as actively promoting quality care to enable the ill person to live fully until their death. Fourthly, there was growing awareness that the mind and body were inextricably linked and that the approach of "total care for total pain", advocated by Dame Cicely Saunders, was necessary in developing a more embodied approach (Clark, 2002).

Small (2001) states that the approach advocated by Saunders is only achievable through the application of a holistic, multidisciplinary view of terminal care. The shift in emphasis

from “physical cure” through medical treatment, to “total care” of the patient is referred to as a “biopsychosocial approach”. This holistic approach was later depicted by Twycross (1995) as a triangle containing three major components: symptom relief, psychosocial support, teamwork and partnership (Oliviere, Hargreaves, & Monroe, 2000). To maintain an integrated holistic approach to palliative care, all sides of the triangle need to be equally effective and active in the care of the ill person and their family. Teamwork and partnership refer to the relationship between members of the multidisciplinary palliative care team, the ill person and family members. Saunders (2001) also points out that during her time as a medical social worker, she learnt about the importance of the family’s role in providing care. Based on these experiences, she made the whole family an integral part of her approach to hospice care from the outset. In doing so, she believed that the type of care advocated by hospice is able to transcend cultural and economic boundaries. Within this paradigm, the whole family is regarded as the care-giving team with its own roles and needs. Given this precept, care at home is one of the corner-stones of palliative care (Saunders, 2001).

Another description of the holistic nature of palliative care is provided by von Gunten (2002) who describes the four domains of palliative care as being physical, psychological, spiritual, and social (family). In a very similar manner, Durie (2001) has developed a model of health and well-being for Maori that applies these concepts to all areas of health. Durie refers to the Whare Tapa Wha Model of Maori health which includes four dimensions: taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical), and taha whanau (extended family). This view of health, as a four-sided construct, is compared to the four

walls of a house, whereby all four dimensions (walls) are required to maintain stability. This model provides an empathic fit with contemporary Maori views of well-being. Ellershaw and Ward (2003) state that the hospice model has now become widely accepted as an excellent model of care; however, the continuing challenge is to transfer the high standard of care advocated by the hospice model to other health-care settings and to patients with other diseases apart from cancer.

1.5.3 Differences in models used to provide palliative care services

The different models that are used to establish palliative care services have been reviewed to emphasise that palliative care is a philosophy of practice, applied in a variety of situations. The lack of a standardised approach to the provision of palliative care services may, in part, be due to the way in which palliative care has developed. Critchley, Jadad, Taniguchi, Woods, Stevens, Reyno, and Whelan (1999) suggest that the development of palliative care has been “reactive rather than proactive” and developed by certain groups of people to meet the needs of specific populations. Canadian research also indicates that there is little standardisation of the level of care received by patients at the end of life (Bruera & Lawlor, 1998). A similar issue is identified in America; research indicates that there is variability in the amount and type of care provided for the seriously ill (Meier, 2004). There is also a need for guidelines that can assist the health professional in deciding when to discontinue treatment (Charatan, 1999). Other contributing factors are the variation in type of care (home, hospital, long-term care facilities, residential hospices, and day programmes); the multidisciplinary nature of service delivery; the different types of funding available, and whether the service is catering to an urban or rural population

(Critchley et al., 1999). There are also differing policies governing the amount of time people can spend in hospice and the frequency with which they can be admitted. Different population groups also have varying needs, and different countries use slightly different models of palliative care service delivery.

Developing countries tend to have less access to analgesic medicines that can relieve the pain associated with terminal illness. The research conducted by Murray, Grant et al. (2005) highlighted the different needs of two populations: Scottish and Kenyan patients. Kenyan patients tended to be concerned about the physical pain associated with their illness and also indicated that they had financial concerns. Scottish patients indicated that they were most concerned about facing and dealing with their emotional pain. In Islamic countries, patients are often in advanced stages of disease before being referred to palliative care services. This problem is compounded by the lack of palliative care facilities and the lack of specialist training in this field (Al-Shari, 2002). One of the reasons for little palliative care being received is late referrals to palliative care services.

Timely access to palliative care services in the form of hospice care or hospital-based palliative care is an issue raised by a number of authors (Carter et al., 2002; Finlay, Higgenson, Goodwin, Cook, Edwards, Hood et al., 2002; Heilig, 2003; Massarotto, Carter, MacLeod, & Donaldson, 2000; Murray, Grant et al., 2005). In America, only 20-30% of people who are dying are receiving hospice services (Heilig, 2003). Palliative care is usually provided by teams of health professionals working in a variety of organisations, such as hospices and specialised palliative care units, as well as within the main hospital

system. By January 2000, there were more than 6560 such teams in 87 different countries around the world. More than 3600 of these teams were in North America; 933 were in the United Kingdom; and over 350 were in Australasia (Finlay et al., 2002). However, empirical evidence is yet to be gathered that clearly shows what approach to palliative care, if any, provides the best care.

1.5.4 The modern hospice movement 1970s-present day

Three changes that had the potential to improve care of the dying in the United States were outlined by Callahan (1995). First was the advanced directive movement with its living wills legislation in the early 1970s. Second was the development of the hospice movement creating a different institutional milieu for the care of the dying. Third was the beginning of courses and training for people in the speciality area of palliative care. The hoped-for improvements many had anticipated have not been as forthcoming. Cases such as that of Karen-Ann Quinlin in the United States in 1976, and the Lesley Martin case in New Zealand in 2004 (wherein a daughter was prosecuted and jailed for ending her terminally-ill mother's life) are still fought in court rooms. Advance directives or living wills make little difference to how a person is actually treated. Many health professionals still receive little or no training in how to deal with the dying, and many Americans still see death as the enemy of an efficient and well-managed life (Callahan, 1995).

There were also major advances in symptom relief and pain management in the 1970s, and many people working in the health field were actively advocating the use of such measures for the terminally ill (Lamerton, 1973). Providing this type of care, however, required a

shift in priority for medical staff; and in order to meet not only the physical, but also the emotional and spiritual needs of dying patients, medical staff would either need further training or, as was suggested, specialty units could be developed to provide these services. Although the development of hospice care was still in its infancy, it was regarded as the most appropriate approach to the care of the dying patient (Lamerton, 1973).

The modern hospice movement, therefore, developed as an alternative paradigm of care for people with incurable physical illnesses (Small, 2001), and provided people with a way to achieve a dignified death (Ellershaw & Ward, 2003). As the original founder of the modern hospice, Dame Cicely Saunders was a qualified medical social worker, physician, and nurse, who opened the first modern hospice, St Christopher's, in South East London in 1967 (Ellershaw & Ward, 2003). The first American hospice was opened in 1973 (Gordon, 2003). The first hospice in New Zealand was The Mary Potter Hospice, which opened in Wellington in 1979 (AHS, n.d.a). Following the ideology of British hospices, Finland opened its first hospice in the late 1980s (Sand, 2003).

Dame Cicely Saunders is the patron of the modern hospice movement (AHS, n.d.b; Small, 2001). She was working as a medical social worker in 1948 when she was inspired by the experiences of a patient with inoperable cancer. The patient, David Tasma, and Dame Cicely, discussed the need for more adequate pain control and for the need to have time to prepare for death. To begin meeting this goal, Tasma bequeathed 500 pounds to Dame Cicely Saunders upon his death (BAH, n.d.).

1.5.5 Palliative care services

The word “hospice” is often used today to describe a philosophy of care as well as a place of care (BAH, 2005). The principles of hospice care can be applied in many settings, such as within the main hospital system, day care programmes, home hospice services (Carlsson & Rollison, 2003; Gomes & Higginson, 2006), and residential hospices, to name a few (Clark, 2002; DeSpelder & Strickland, 1983). The first hospital palliative care service started in 1974 in New York, 1977 in the United Kingdom, and 1985 in New Zealand (Carter et al., 2002). In an attempt to implement palliative care services within the wider hospital institution, thereby making this service available to more patients, The Brooklyn Hospital Centre in New York introduced a trial palliative care model (Alley, 2002). This was based on a patient-centred approach, managed by specially trained nurses called Palliative Care Experts (PCEs), and supervised by a physician. An initial interview was conducted with patients referred to the palliative care experts to determine what their needs were and to then communicate this to the attending physicians. Secondly, the palliative care experts would assemble an ad hoc team to provide the services these patients required. Once the initial two-year grant had run out, the service was reviewed and it was found to be very popular with the patients, their families, and the staff; and it was well utilised, as well as highly cost efficient. It also had a positive influence on the culture of the hospital, although some physicians remained resistant to its use (Alley, 2002).

Worldwide, there are a variety of models of hospice care, and each has advantages and disadvantages (von Gunten, 2002). Von Gunten explains that when a hospice is based within the main hospital, it is more accessible to doctors and patients, but may have a very

clinical atmosphere. Hospice ideals encompass notions of patient autonomy, involvement, and empowerment, and the patient's right to self-determination; ideals that can be lost when hospice is incorporated into mainstream health care institutions (Scott, 1999). Hospices that are built as specialist units manage to overcome the medical institutional "cold sterile" look, but may be set aside as "places to go to die" (von Gunten, 2002). Similarly, in a study examining how best to provide palliative care (Alley, 2002), the information yielded from focus groups and interviews with health professionals highlighted that virtually no-one wanted to have specialist units or specialist teams; these were viewed as "death squads". Although hospice has been successfully established as a place of non-aggressive comfort care, it does not meet everyone's needs (Alley, 2002). Some units are very structured and have set visiting hours, which can be a disadvantage for patients and family members; but such settings do allow the patients to rest and to have some quiet time in the unit (von Gunten, 2002). Whilst some units still involve patients in tests, therapy, and medical procedures, others do not (Bruera & Lawlor, 1998).

1.5.6 Palliative care services: New Zealand

In many countries, the choice of hospice care that is provided is limited, or may not exist at all. In New Zealand, for example, there are no hospice facilities in many parts of the east coast of the North Island, the West Coast of the South Island, Wairau, or Central Otago (MOH, 2001). The lack of hospice facilities and the limited number of hospice beds has contributed to increasing numbers of people dying in acute hospital settings. In 1996, it was noted that approximately 60% of deaths occurred in New Zealand hospitals each year (Carter et al., 2002). As of 2001, domiciliary nursing services were provided by 19 of the

32 New Zealand hospices. There were also 22 hospital-based district nursing schemes offering support to the terminally ill at home (MOH, 2001). This situation confirmed the need for further development of hospital-based palliative care services.

The first hospital palliative care service in New Zealand was established in 1985 in the Waikato area, with similar services also developing in Auckland and Christchurch hospitals. There is also a children's palliative care service offered by Starship Children's Hospital in Auckland (MOH, 2001). However, by 1998 there was still no hospital-based palliative care service available in Wellington. This fact prompted Mary Potter Hospice in Wellington to fund a pilot service. However, the scheme lasted only 18 months as funding ran out and the hospital was unable to secure funding to keep the service running. After one year of operation, the service was evaluated and found to be popular with hospital staff; over 90% agreed that it improved their ability to provide care and symptom control. It was found, however, that the service was not as effective at meeting the patient's spiritual needs, and there were multidisciplinary differences in responses about the effectiveness of the service in discharge planning and staff support. Interim funding was granted in the early 2000s to re-establish the palliative care service (Carter et al., 2002). Mary Potter Hospice has also continued to be involved in negotiations with the government to secure ongoing, and increased funding for palliative care services in New Zealand (Mary Potter Hospice [MPH], 2008).

An outline of palliative care services in Christchurch was provided by the Canterbury District Health Board (CDHB) in 2002. This outline highlighted various issues in the

provision of palliative care services in the region. Canterbury has hospice and hospital palliative care services available, “but there are only 3.1 hospice beds per 100,000 population which is below the national average of 4.0 per 100,000” (CDHB, 2002, p. 4). This shortage of beds results in many patients being placed in aged care hospitals and rest homes; environments not designed or suited to people under the age of 65. It is, however, more cost-effective to place people in private facilities such as these, than it is to keep them in acute hospital settings. The Christchurch Oncology Department receives a certain amount of funding each year so they can continue to fund long-term care for cancer patients; however, in 2002, the amount of funding used was almost double that received for this purpose (CDHB, 2002).

Organisations such as Nurse Maude in Christchurch have been running district nursing schemes and caring for dying patients in their homes since the 1800s. In a book by Allan (1996), the Christchurch-born Nurse Sybil Maude (1862-1935), is quoted as saying in 1908:

There are many whose lives are falling to a close, and it falls to the nurse’s lot to tell them so, then it is that so much lies in our power to comfort and strengthen them with words of hope. A young man once said to me when he knew he could not recover, ‘well, nurse, I look upon death as an event in life,’ and so it is. (Allan, 1996, p. 35)

Death was regarded as a natural event that was discussed openly with patients once people were aware that death was imminent. Nurse Maude believed that these discussions helped the dying prepare for death.

1.6 Structure of Thesis

Due to the overwhelming amount of literature concerned with palliative care, death, dying, and bereavement, I have begun Chapter Two, the literature review, by clarifying search boundaries by discipline, speciality area, and topic relevance. Through this process I identified four relevant major themes which are explored in Chapter Two. The first theme is quality of life, a topic area that appears to be rather contentious due to unreliable findings and the use of flawed research tools. The second theme is that of communication, and is discussed in relation to breaking bad news, diagnosis, individual and cross-cultural differences in disclosure, decision making at the end of life, health professionals' apparent inability to accurately diagnose or convey dying, the role of optimism in prognosis, and, finally, preparedness for death. The themes of quality of life and communication that are discussed in Chapter Two are later interwoven into the findings chapters and examples are provided to illustrate the relevance of the theme to the participants' experiences. The third theme in Chapter Two relates to the issue of intervention in palliative care that is currently being debated in the literature. This issue is reviewed by considering power dynamics, the medicalisation of dying, avoidance of death, the management of death, and prognosis and cultural views. In closing Chapter Two, the last theme is the complex role and practice of social work in end-of-life care. There is also further more specific literature introduced in the findings chapters (Chapters Five to Eight) as it becomes relevant in discussing the themes and issues that emerged from the data analysis.

Chapter Three is primarily focused on theory and, in particular, on the broad theoretical lens with which to view the data and findings. Consideration is given to the use of the

ecological perspective as a metatheory within which theories are able to be incorporated and challenged to be holistic. Currently, broadly ecological perspectives position social work analyses; however, such perspectives only provide broad frameworks, and other more explanatory theories are required to guide practice and develop knowledge. These other theories include theories of loss and grief, such as Stroebe and Schut's (2001) Dual Process Model (DPM).

The dual process model provides an effective orientation for social work in palliative care. By combining the dual process model and the ecological perspective, a theoretical lens is developed which provides a way of understanding the participants' journeys from diagnosis to the end of life. Applying an ecological framework in conjunction with theories of loss and grief, encourages the exploration of environmental factors in the process of loss and grief. It also leads to the development of a reflexive theoretical base from which to understand the complex, multilayered, multisystemic experience of grief and its manifestations. The use of a metatheoretical perspective, such as the ecological perspective, is suited to the current research which takes the person in their wider environment into account. Drawing on an ethnographic research methodology also allows the collection of data from the wider cultural environment in which the terminally-ill individual is placed; this methodology is discussed in Chapter Four.

As well as discussing qualitative research and ethnography, Chapter Four: Methodology also considers the role of the self in ethnography, topic selection, research participant recruitment, data collection, data analysis, and methodological and ethical issues. There are

two types of data analysis employed in the current study; these are narrative analysis, and grounded theory. The use of each of these forms of analysis is also discussed in Chapter Four.

Chapters Five to Eight explore the data obtained during the fieldwork. Drawing on narrative analysis, Chapter Five presents the stories of the eight participants who were diagnosed with incurable cancer and referred to the community palliative care team. These stories are analysed by utilising Lawler's (2003) conceptual, interpretive narrativity. Chapter Five also explores the first research aim: *to understand how individuals and families make meaning from the experience of being referred to palliative care services*. The retrospective nature of the data used in this chapter is due to the fact that I was not involved with the participants at the time of their diagnosis. They were, however, eventually able to tell me the stories of diagnosis that began their journeys. From this point onwards, I was able to collect the data as I walked alongside participants for the remainder of their journeys; the findings from the analysis of the data are presented in Chapters Six to Eight.

In Chapter Six, a case study format is used to present the data. Although the themes on which I focus emerged through the process of grounded theory data analysis, the chapter also fulfils the second research aim: *to explore how shared understandings are drawn on by an individual and their family to make meaning of the process of engagement with palliative care services*. In this chapter, I discuss the changing landscape that participants encountered as they moved between their home environments and the health system. The

themes that emerged from the data analysis were: home and identity, the gendered nature of place, geographical fantasy, cultural markers, and contested places. Chapter Six firmly locates the theme of “place” as one of the core concepts in this thesis. The very nature of an ethnographic study involves situating participants in certain environments in which their experiences occur. Palliative care services are provided in particular places, environments that have a direct effect on participants. Therefore, the nature of these places is explored in Chapter Seven.

Chapter Seven considers the embodiment of place and space by providing an analysis of two primary hospital spaces: the chemotherapy suite and the oncology ward. These two environments are explored by examining their location, appearance, contents, and theme. The two environments are then contrasted, and the behaviour of people located in these sites is also explored. Finally, a systematic analysis and a critical contrast are conducted to provide an overarching image of the two sites. The final result of this analysis is a contrast of two images, the chemotherapy suite as the place where disease is being tamed, where there is a triumph of medicalisation over death, and the oncology ward with its image of illness and death. The existential meanings of the two places are profoundly different and held quite diverse implications for the participants who spent time in them.

Chapter Eight, the final findings chapter, presents the end stages of each participant’s journey; a journey within which their identity was once more transformed as they shifted from being “people living with cancer”, to “people dying with cancer”. As I move through this chapter, it is evident that the ill participants’ roles in the research diminished as they

moved closer to death and were less able to interact. Conversely, family members became more fully involved in the research process as they gathered around the beds of their loved ones. As noted earlier, there were a total of 83 family members involved in this research. This chapter also provides answers relating to the third research aim: *to explore how the individual and their family understand their decisions about end-of-life care.*

Chapter Nine explores the two core categories that arose through the process of data analysis. The first core category of “time and place” was developed from the analysis and writing of Chapters Five to Seven. These Chapters discussed the following themes: participants’ stories of diagnosis; their cultural identity within their home environments; their enculturation into the health system; and an analysis of two primary places occupied by the participants. The second core category of “preparation for death”, which arose from the analysis and writing of Chapter Eight relates to the discussion of family members’ awareness of the transition to late-stage cancer and the participants’ awareness of, and preparedness for, the end of life. In particular, I consider the intervention-focused culture of the chemotherapy suite, contrast this with the palliative care approach, and consider the different journeys, trajectories, and outcomes that arose for the research participants in these settings. These trajectories are presented in Diagram 5: The Roadmap. I then move into discussion of the issues that arose from the research and the resultant considerations for social work practice, palliative care and further research. I close Chapter Nine by reflecting on the ethnographic methodology and the implications for future research.

The participants each took different paths to reach the same destination, the end of life. As I walked alongside the participants on their journeys, I was given the honour of sharing their darkest moments of despair and their brightest moments of enlightenment. These are their stories.

1.7 Note on Language

In Aotearoa New Zealand, there is an abiding commitment to the Treaty of Waitangi, signed in 1840 by representatives of the British Crown and Maori Chiefs representing the indigenous tribes. This commitment ensures that the needs of the indigenous people are paramount in the provision of health and welfare services. Some limited Maori language words are commonly used in conjunction with the English language in various media, including television and radio. Health and welfare policies and documents pay particular attention to the needs of the indigenous Maori population and other ethnic minority groups. Within these documents, translations are increasingly written in Maori and Pacific Island native languages. As the current thesis includes Maori participants, and is conducted within the cultural milieu of Aotearoa New Zealand, Maori terms are at times used; these terms are defined where they occur. This is not, however, a thesis that set out to focus on culture as denoting ethnicity, and, as a Scottish European researcher, I have not attempted to provide a comprehensive overview of, for example, Maori mourning rituals. I did feel profoundly privileged to be invited to join whanau (families) in such significant processes and greatly valued the explanations they provided me of these. For more comprehensive literature on this topic see Oppenheim (1973) *Maori Death Customs*.

Chapter Two

A Review of the Literature

*We perhaps forget the root out of which the word 'care' arises-it is the same root as for our word 'culture.' To care is to become one with another, to join with a person in the greater 'culture' of mankind, of life itself. For, in truth, there is no 'other.' There is just being, experienced from different focal points.
(Levine, 1982, p. 171)*

2.1 Introduction

The task of evaluating literature on palliative care requires a systematic approach with clear search boundaries and definitions because of the sheer bulk of the available literature (Tieman, Abernathy, Fazekas, & Currow, 2005). It has been suggested that this difficulty is compounded by several factors. The field of palliative care spans many disciplines, including: social work, medicine, psychology, gerontology, religion, and nursing. It also spans many specialities and diseases including: adult cancers, child cancers, cardiology, HIV and AIDS, Alzheimer's disease, and age-related illnesses. Information about palliative care is published in journals and books relating to each of these disciplines, and to many diseases, including those already mentioned and others (Tieman et al., 2005). Therefore, rather than providing an exhaustive account of palliative care literature from each of these sub-fields, the following literature review has been limited to a focus on issues pertinent to the current research. Theoretical and empirical literature is also referred to throughout the body of the thesis. Within this chapter, I will consider the relevant major themes arising from the literature search. These themes are: quality of care, communication, diagnosing dying, optimism, standardisation of care, transition from intervention to palliative care,

medicalisation of dying, death as failure, prognosis and cultural views, the good death, and the management of death. Then I will discuss social work literature and the contemporary issues being raised in palliative care and social work. Issues relating to social work's role in end-of-life care dominate this final section.

2.2 Quality of Life and Quality of Care

Attempts at clarifying the best approach to the care of the dying have led to numerous studies that have focused on the quality of care and the quality of life of patients in palliative care facilities (Carter et al., 2002; Critchley et al., 1999; Ellershaw & Ward, 2003; Finlay et al., 2002; Fordham & Dowrick, 1999; Sand, 2003; Scott, 1999). Aranda (2001, p. 572) suggests that the ability of professionals working in end-of-life care to critically consider practice is hindered by a number of oppressive behaviours, which he refers to as “tyrannies”. He suggests that the “tyranny of niceness”, a term he credits to Annette Street (1995), silences any dissenting voices in the field. This term is explained by Aranda (2001) as reflecting the personalities of people who are often drawn to work in this area; people who are genuinely committed to those who are dying and their families: nice people. The rhetoric of palliative care has become so widely used and accepted that people often describe their work as open-minded, holistic, person- and family-centred, without critically analysing it. With growing emphasis on health outcomes, and the need for accountability in order to receive ongoing funding, the tyranny of niceness inhibits workers from challenging others in their environment to critically engage in workplace analysis (Aranda, 2001). International research also indicates the need for the development and provision of palliative care services for people who are dying of diseases other than cancer

(Addington-Hall & Karlson, 1999; Grbich, Maddocks, Parker, Brown, Willis, Piller, & Hofmeyer, 2005; Murray, Boyd, & Sheikh, 2005).

A systematic review of studies was conducted by Critchley et al. (1999) to determine whether some systems of palliative care were more effective than others. Critchley et al. state that a similar review by Rinck et al. (1997) on randomised control trials of comprehensive palliative care found many limitations. In their own review of comparative studies they also found many limitations. The authors established a set of predetermined inclusion criteria for the studies in this systematic review. Only 41 studies of the 284 citations found in their initial searches met the inclusion criteria. Of these 41 studies, one of the major flaws was the generally poor reporting of the studies. The primary deficiencies were a lack of definitions of major terms such as palliative care, hospice, home care, and conventional care, which implies a universal understanding that does not exist. Furthermore, control groups were not adequately described, and the clinical importance of the reported outcomes was unknown in a number of studies. Most of the studies focused on the individual's perspective as opposed to systemic issues. There was also a lack of studies on non-cancer patients and paediatric populations. The conclusion of their review was that it was almost impossible to draw conclusions about the best system of palliative care due to the methodological limitations in the 41 studies that were reviewed (Critchley et al., 1999).

A systematic review of the literature was undertaken to establish whether there was a notable effect of the palliative care teams when compared to non-specialist health care services (Finlay et al., 2002). Data extracted from 43 studies provided information on the

place of care. Places of care that were included in the study were: hospital palliative care services, home care services, inpatient hospices, and services that integrated inpatient hospice and home care. In a comparison of non-hospice and palliative care services, the results showed a positive benefit for specialised palliative care teams. Carer satisfaction was one of the most consistent benefits of specialised care. Improved pain and symptom control were found in some of the studies. In general, the review supported the effectiveness of a variety of palliative care teams. The least information was available on hospital-based palliative care teams and the most information available was about home care services (Finlay et al., 2002). These authors suggest that much of the evidence in the 43 studies that they examined was of poor quality or flawed.

The comment made by Finlay et al. (2002) that much of the evidence in the studies they examined was of poor quality or flawed is reiterated by Fordham and Dowrick (1999). In their review of studies that examined the quality of life of dying patients, they state that the “overall quality was poor” and there was a dearth of information on patients dying from non-neoplastic conditions (diseases other than cancer). These authors explored evidence from studies that examined the quality of care of dying patients in specialist and general practitioner care. Like Finlay et al. (2002), Fordham and Dowrick considered a range of places where death occurs. This included general hospitals, hospices, specialist palliative care facilities, nursing homes, and peoples’ own homes under the care of their general practitioner (GP). They found that the bulk of the available information was on patients with cancer and that little information existed about the care of patients dying from other causes. Their findings indicate that the claim that the care of the dying is improving cannot

be made with any certainty. They state that while patients for whom care has improved are in the minority, this group will have had access to specialist palliative care teams. They also argue, as do Ellershaw and Ward (2003), that the practice of a wide range of clinicians needs to become more consistently changed and improved if the quality of care for patients dying in other settings is to be improved (Fordham & Dowrick, 1999).

In 1959, Bailey pioneered a study of the social needs of 155 patients who had incurable lung cancer. Bailey concluded that the quality of care for people with a terminal illness depended on: the family's ability to care for the person at home, uncertainty about terminal care facilities, familiarity with the main hospital systems, the preference to return there instead of going to a terminal care facility, the severity of medical problems, the family's relationship with their own GP, and the family's ability to communicate openly about the diagnosis (Saunders, 2001).

Quality of care is one of the goals of palliative care (Critchley et al., 1999; Ellershaw & Ward, 2003; Hawthorne & Yurkovich, 2003). Randell and Downie (1996) argue that what is vital is that palliative care is provided in a caring, sensitive, warm, and ethical manner. They also state that establishing the quality of care of terminal patients is fraught with difficulties, as most of the quality indicators used in health, such as rates of cure, are not as relevant in palliative care. It is widely accepted that quality of care for the terminally ill has improved since the inception of the modern hospice movement (Scott, 1999). The effectiveness of hospice care was evaluated by Sand (2003) in a study of three Finnish hospices. The research focused on the quality of care received by patients, the rituals and

traditions surrounding end-of-life care, and the expectations of the staff, family, and the dying person. Sand explains that the needs of the individual who was dying, as well as the needs of family members, were well met by the interdisciplinary team and volunteers. The research also highlighted the vital role of nurses and non-hospice workers in caring for the dying (Sand, 2003).

A review of the literature on palliative care and terminal care was conducted by Ellershaw and Ward (2003) to determine the quality of care of cancer and non-cancer patients in hospice and other care settings. The review highlighted a major issue in the care of the dying which was the need for health care professionals to learn how to diagnose dying. One of the findings of the review was that training was required for all health care professionals not just specialist palliative care teams. This was recommended so that more patients with varying types of terminal illnesses, not only cancer, would receive quality palliative care in generic health care settings (Ellershaw & Ward, 2003). The authors call for the development of a clear structure for care provision so that generic workers can be empowered to better meet the needs of the dying.

The issue raised by Ellershaw and Ward has also been raised by Scott (1999). Scott argues that it is debatable how well care is being provided in health care settings in the United Kingdom. She explains that UK research may be biased as much of it is conducted at just one setting: St Christopher's Hospice. She says that whilst there is no doubt that the quality of care being provided at St Christopher's is consistently good, there are doubts about how well it is implemented in other places. Secondly, she warns that a lot of the information on

quality of care is taken from accounts and interviews with family members and carers, and whilst this is valuable data, information from patients themselves (the people actually receiving the care) may provide quite a different perspective. Research using terminally-ill patients as participants is less common due to practical and ethical issues (Scott, 1999). The reliance on information from caregivers is also discussed by Fordham and Dowrick (1999), who point out that there is a problem in accepting carers' opinions as the proxy opinions of the deceased. They state that studies that draw on the experiences of the dying patient are required.

2.2.1 New Zealand research and quality of palliative care

A survey of New Zealand health professionals working within a new hospital-based palliative care service was conducted to determine whether there was a perceived impact of the service on patients, families, and staff, and to determine where improvement might be required (Carter et al., 2002). The researchers also wanted to discover any differences in responses from varying groups of health professionals, including doctors, nurses, social workers, and speciality services. In general, all respondents agreed that there was a positive effect of the service on the quality of patient care. More nurses than doctors agreed that symptom management and understanding the role of palliative care services were improved. The nurses did not agree, however, that patients' spiritual needs were addressed. Over 90% of the health professionals agreed that the palliative care service had assisted them in providing better quality care for their patients. Only half agreed that it had provided better discharge planning and staff support. The need for better communication was one suggested area for improvement, as was the need for more adequate hospital

facilities for the long-term care of dying patients. The provision of information and education about palliative care and pain management, for patient, family and staff, was another area of needed improvement (Carter et al., 2002).

2.3 Communication

When discussing the delivery of “bad news” to the ill person and his or her family, Robert Buckman, a medical oncologist, said, “If we do it badly, they may never forgive us; if we do it well, they may never forget us” (Buckman, 2002, p. 325). Yet very little training is given to medical students on how to deliver bad news. Buckman (2002, Cover page) defines bad news as “any news that adversely and seriously affects an individual’s view of his or her future”.

Saunders (2001) refers to a number of early articles and studies exploring this topic, which were published in the 1950s and 1960s. These include Player’s (1954) article, “Casework in terminal illness”, and Aitken-Swan and Easson’s (1959) article, “Reactions of cancer patients on being told their diagnosis”. Both studies investigated the quality of support being provided to families caring for a terminally-ill family member at home. The researchers conducted follow-up interviews to ascertain the nature of the care the patient had received. The research also explored the reactions of patients when their diagnosis was revealed to them. It was found that the majority of patients with curable cancer were able to benefit from and accept the truth about their illness. In 1960, Birley conducted another research project with 155 terminally-ill participants, and supported the finding that it was vital for people to know about their diagnosis. Birley explained that patients were often

very accepting of their diagnosis or had already suspected that they were gravely ill for a period of time. The findings indicated that patients had been able to discern a change in the treatment they were receiving from staff, and may have taken the decline in staff involvement as an indication of their own “failure” to be cured (Saunders, 2001). This early research was soon followed by several other studies that explored the issue of patients’ awareness of their terminal illnesses (Foster, 1965; Glaser, 1993; Seale et al., 1997).

Another early study exploring communication about prognosis was conducted by Foster in 1965. This study was conducted to determine what influence social workers could have on the management of terminal illness. Foster concluded that the staff “culture” of not informing the patient of the severity of their illness created an unspoken “cultural understanding” of silence about death and dying. The ward culture of silence about death and dying was an understanding soon internalised by families who then made decisions for their dying family member as opposed to discussing issues with them. During the study, Foster became involved in the successful resolution of three different cases, whereby the ward culture of silence was broken and a new, more open approach to discussing a patient’s illness was pursued. Foster concludes her research with a warning that changes in ward culture will inevitably bring new challenges for staff; one such challenge that she highlights is the variation in individual patients’ abilities to cope with the reality of their prognosis (Foster, 1965). Citing studies carried out in the 1960s and ’70s, Baile, Buckman, Lenzi, Gloger, Beale, and Kudelka (2000) explain that communicating bad news about a diagnosis was often regarded as damaging and inhumane, and, therefore, avoided.

An awareness of individual differences in the need for information and the need to discuss death was highlighted by Seale et al. (1997). Their study focused on the consequences and implications inherent in having, or not having, knowledge about imminent death. This survey of 3696 relatives and friends of someone who was dying was carried out in 20 areas of the UK and results were compared to an earlier study conducted by the authors in 1969. The study also drew on notions of death awareness from Glaser and Strauss's (1965) book, *Awareness of Dying*, which discusses issues around open and closed awareness of death and dying. Seale et al.'s 1997 survey indicated that people who were open or aware that they were dying were more likely to be able to plan for their death and, therefore, more able to die at home. They were also more likely to access hospice care and to have talked about euthanasia.

It is suggested that underlying these patterns, and in contrast with some other cultures where awareness of dying is seen as less desirable, people dying in Anglophone countries are particularly concerned to maintain control over projects of self-identity. Their approach to death is a reflection of this individualism. (Seale et al., 1997, p. 477)

In more recent times, communication in end-of-life care has received attention due to the growing awareness of its vital role in striving for "the good death" (Baile et al., 2000). Kirk et al. (2004) conducted a qualitative study using interviews with patients and family members to elicit their views of disclosure and information sharing during the course of the patients' illness. Many participants indicated that they were unhappy with the initial process of disclosure about the diagnosis. The researchers found that when trust had been compromised at the initial disclosure of the illness, it often remained an issue throughout the participants' involvement with health care specialists. They found that there were six attributes that were important in conveying information. These were: "playing it straight,

staying the course, giving time, showing you care, making it clear, and pacing information” (Kirk et al., 2004, p. 4). They also found that these attributes in communicating information were important at every phase of the illness, from initial diagnosis to end-stage care.

A difference in communication needs across various cultural groups has also been noted in the research. The ability of an ill person to make decisions about treatment options rests on their understanding of their diagnosis. Yet disclosure of information to cancer patients varies worldwide and within different ethnocultural groups (Sweeney & Bruera, 2002). In southern Europe, Japan, and South America, telling patients the truth about their illness is less common than in North America, where almost all patients know the truth (Sweeney & Bruera, 2002). A cross-cultural study was conducted by Kirk et al. (2004) who found that open communication was regarded as desirable by almost all of the participants despite their different cultural backgrounds. From their total of 72 participants, they divided the research groups into two. One group consisted of 37 patients, and the other group consisted of 35 family members. The patients were asked if they wanted to know the diagnosis of their illness. All the patients wanted to know their diagnosis and two patients said that they would not want family members to know their diagnosis. Later, however, they did tell their family members about their diagnosis. All 35 family members thought that it was important for the patients to know their diagnosis. The authors point out one limitation in the research. Access protocols involved self-selection which means that although they were able to draw on participants from a range of cultures, families experiencing conflict around communication issues may not have been willing to volunteer for the research. This would be likely to create a certain amount of research bias in the results.

A similar topic is explored in a study by Fainsinger, Nunez-Olarte, and Demoissac (2003) entitled, “The cultural differences in perceived value of disclosure and cognition: Spain and Canada”. In this study, the researchers looked at the amount of sedation used at the end of life and examined the notion that more sedation is used when patients are unaware of their impending death. Spanish patients tended to be more heavily sedated than Canadian patients, and had also engaged in less discussion about their illness and dying. In their findings, Fainsinger et al. indicate that what their study highlights is a perceived difference in disclosure practices across different ethnocultural groups.

A comparison of the attitudes of medical students in England and medical students in South Africa towards people who had a terminal prognosis was conducted by Lloyd-Williams, Dogra, and Morake (2003). Findings of the study indicated that South African medical students believed less in patient autonomy and the patient’s need for openness about death and dying, than did the English students. Disclosure of information about the end of life was seen by South African students as a decision made by the doctor involved in care; the English students, however, believed that disclosure of this information to the patients was a necessary part of their role. The South African students indicated that they were less likely to find end-of-life care rewarding, but more likely to find curative treatment rewarding. The researchers suggest that this belief, held by the South African students, may be due to the significant number of people who die at home because of the HIV epidemic, and the resulting belief that hospitals are only for curative treatment. One other finding was that the South African students responded positively to the role of spiritual leaders in care for the dying, but the English students responded less positively (Lloyd-Williams et al., 2003).

The issue of communication in making decisions about cancer treatment has also been raised in the literature. In one such study, 59% of cancer patients wanted their doctors to make decisions for them regarding treatment (Degner & Sloan, 1992). Following attendance at an oncology clinic, a group of 1012 women with breast cancer were surveyed and the findings showed that 34% wanted the doctor to make their treatment decisions, 22% wanted to choose their own treatment, and 44% wanted to collaborate with the doctor in making this decision (Degner & Sloan, 1992).

A lack of communication between medical staff, patients, and families can also lead to individuals and families being unprepared for bereavement (Ellershaw & Ward, 2003). This can occur for a few reasons, one of which is the lack of training received by general hospital staff to assist them in dealing with death and dying, or to assist them in delivering “bad news”. Another common reason is the varying levels of disclosure about the illness and prognosis between members of the multidisciplinary team. This may occur as an attempt to maintain a patient’s right to autonomy (the right to know or not know) or an attempt to be culturally appropriate; issues that are fraught with inherent difficulties (Ellershaw & Ward, 2003).

2.3.1 Communication and diagnosing dying

It is argued that the reason many people do not receive palliative care is because health professionals are sometimes unable to “diagnose dying”. Diagnosing dying is, however, fraught with tension as it may imply “giving up” or “letting go of hope” in a hospital culture focused on “cure” (Ellershaw & Ward, 2003), or it may be interpreted as a “death

sentence” by patients (The, Hak, Koeter, & van der Wal, 2001). Ellershaw and Ward (2003) also argue that the most important factor in diagnosing dying is open and clear communication between all members of the care team. All members need to agree and to acknowledge that the patient is dying so that the type of care being provided for the patient and family is clear and focused. It also allows all members of the care team to speak openly with the patient without giving them confused messages; if appropriate, it also allows team members to speak honestly and openly with family members. The inability to diagnose dying, however, leads to a large number of people dying with uncontrolled symptoms. It also means that the needs of the dying person and family members may not be met, and that death may occur in an environment that was not chosen by the ill person and their family. Apart from leading to a distressing death, this can also lead to complicated bereavement for unprepared family members and friends of the deceased (Ellershaw & Ward, 2003).

2.3.2 Communication and optimism

There are several barriers to effective communication discussed in current literature. One such barrier is “false optimism”. An ethnographic study carried out in a Dutch hospital on small cell lung cancer found that after receiving one course of chemotherapy most patients were more optimistic about their recovery than were their doctors (The et al. 2001). This may in part be due to the fact that this type of cancer is highly responsive to the first sessions of chemotherapy. This results in doctors, patients, and family members engaging in a “recovery plot”, the person was well, now they are ill, they can be made well again. Upon recurrence though, it is not so successfully treated, although treatment does continue

and is the primary focus of doctor/patient communication. The et al. (2001) observed the resultant “recovery stories” that developed for patients, doctors, and family members. Adherence to the recovery story, and, therefore, “false optimism” was maintained even when patients and their doctors knew that death was imminent. There appeared to be a doctor/patient collusion not to discuss dying, but to focus instead on “treatment”. This often resulted in regrets for family members who were unprepared for death and felt that they had lost any opportunity to say goodbye. It also prevented the ill person from considering other treatment options (The et al., 2001), or from making the move to palliative care.

2.3.3 Communication: New Zealand research

Carter et al. (2002), in their survey of health professionals involved in a New Zealand hospital-based palliative care service in Wellington, found that 5% of respondents believed that better communication was required of doctors and nurses in the service. They also highlighted some important areas where more focused communication was required; these included at the point of referral, during follow-up, and after discharge to the community or hospice (Carter et al., 2002).

2.4 From Intervention to Palliative Care

There are vast differences in the timing of referrals to palliative care, and lack of consistent approaches to determining when it is appropriate to move from treatment or intervention to palliative care. Over the last 10-15 years, much has been written in health care literature about this transition and the need to focus on patient empowerment, advocacy, and self-determination (Scott, 1999). In the following sections, discussion on this topic follows

many lines of thought, including: (2.4.1) cultural view of prognosis (Murray, Boyd et al., 2005); (2.4.2) transitions and power dynamics (Alley, 2002; Scott, 1999); (2.4.3) the medicalisation of dying (Callahan, 1995; Carter et al. 2002; Clark, 2002; Ellershaw & Ward, 2003; Finlay et al., 2002; Illich, 1995; Murray, Boyd et al., 2005); (2.4.4) death as medical failure (Cohen, 2003); and (2.4.5) the management of death (Callahan, 1995; Cohen, 2003; Illich, 1995; Lamerton, 1973; Schwartz & Weiner, 2003).

2.4.1 Prognosis: Cultural views

Murray, Boyd et al. (2005) found that in Kenya the patients involved in their qualitative study were generally accepting of their prognosis, and were very rarely angry about their illness and death. Most participants had strong religious beliefs and felt that there was little point in trying to control their illness; their spiritual beliefs brought them much comfort and emotional support. A diagnosis of cancer for a Kenyan person was seen as the end of searching for a cure and a beginning of the waiting time: “until the home calling (patient 11)”. Very few people engaged in active treatment for their cancer (Murray, Boyd et al., 2005).

2.4.2 Transitions and power dynamics

Alley (2002) and Scott (1999) both discuss the power dynamics they believe operate within the medical system. They both explain that bureaucratic systems of institutional care can, in fact, force patients into a more passive role where they are the recipients of treatment rather than active parties in the decision-making process (Alley, 2002; Scott, 1999). Scott (1999) argues that the nurses’ task of “empowering” patients would be redundant if hospital staff

did not assume power in the first place. What is required, she suggests, is a humbler approach that does not initially assume power and control. She explains that suggesting that patients need to be empowered is a practitioner-based notion of health care. A patient-centred notion of health care allows for the fact that the practitioner has more knowledge about the disease and the treatment options, but only the patient knows what is right for them. They are, in fact, the authority on how they understand the situation and the options being presented to them. Scott suggests that if practitioners could simply understand the notion of shared humanity they would find it relatively easy to see that, just like them, patients have feelings, desires, and views that need to be respected.

2.4.3 Medicalisation of dying

The issue about the medicalisation of dying was emerging into awareness in the 1970s when Ivan Illich wrote *Medical Nemesis* (1974) in which he provided a critique of the medicalisation of death. Death was no longer seen as a natural event, but something to be avoided with the use of technological advances in modern medicine (Clark, 2002). Medicalisation was soon associated with all the negative connotations of a medical profession which was reaching too far in its quest for a cure (Clark, 2002). Illich (1995) claims that medicalisation instilled in people a fear of pain and death that was to be avoided at all costs. The author discusses his own experiences of interactions with the medical establishment. He argues that instead of supporting him to “find strength in the beauty of memories, and to take leave of this world” he was engaged in medical rituals that created unreal expectations (Illich, 1995, p. 1652). Proponents of this line of thinking point to statistics to support their theory.

In the United Kingdom, nearly a quarter of all hospital beds are taken up by people who are in the last year of their life (Clark, 2002). Based on 1999 statistics gathered by St Christopher's Hospice in London, it is estimated that over half of the patients with a terminal illness die in hospital beds and only 11% die in hospice (Finlay et al., 2002). Statistics compiled by the Audit Commission in London, in 1999, indicated that in one hospital surveyed, 47% of elderly patients with advanced dementia or cancer were still receiving invasive treatments up until the last few days of their life (Clark, 2002). Similarly in New Zealand, almost 60% of cancer-related deaths in 1996 occurred in a main hospital setting (Carter et al., 2002).

Awareness of the futility of treatment for some patients and the push for timely referrals to palliative care services reintroduced notions of “the natural death” and “the good death” advocated by Nietzsche in 1966 (Callahan, 1995). Ellershaw and Ward (2003) state that although achieving a good death is an important challenge for all health professionals and society at large, many people still die with uncontrolled symptoms and in distress, and many family members receive little or no support. Murray, Boyd et al. (2005) state that both physical and psychosocial needs have to be met to ensure a “good death”.

2.4.4 Death as medical failure

Lamerton (1973) also explains that within the general hospital system, people who have been unresponsive to medical intervention are often viewed as failures and, therefore, receive little attention. George Soros, who spearheaded and funded the Project on Death in America, also observed that death is represented as “failure” in a medical culture where the

primary focus is to prolong life through treatment and cure (as cited in Cohen, 2003). The aim of the Project on Death in America was to transform the culture around death and dying and establish a new discipline of palliative medicine. Soros, having experienced his parents' deaths, began to consider the way in which death was medically "managed" in America. As part of the project, 70 scholars of diverse backgrounds, such as researchers, academics, and practitioners, met for a week, once a year, to discuss issues such as death, grieving, bioethics, and symptom management. In his article "Pulling the Plug", Cohen (2003) reflects on some of the issues raised at the last gathering.

From an interview with Dr Tony Bak, an Asian-American oncologist from the University of Washington, Cohen (2003) records him as saying:

It's time to write a different story! The cancer story is try against the odds and if you just search the Internet a little more, if you just find the right doctor, and the right treatment, and the right combination, you'll beat this. It is a shopping metaphor—a consumer's viewpoint—that if you just shop long enough you will find an incredible bargain. (p. 280)

What Dr Bak believes, however, is that we need to rewrite the cancer story, and in it people need to be able to say, I know my body is dying; families need to know what to reasonably expect as an outcome of treatment decisions; and people need to know that there is a way to transform dehumanising situations into profoundly peaceful experiences of death. In summing up his interview with Dr Bak, Cohen (2003) states that one of the main messages from the discussion is that we need to consider how medicine has transformed end-of-life

care. With the information health care professionals now have about death, dying, and terminal illness, people have more choices and more opportunities to die in a manner that is congruent with the way they lived. Cohen argues that “the public needs to increase its expectations of what medicine can do to improve how we die” (p. 283). In this way, the individual still maintains control over their life and death.

2.4.5 The management of death

The notion of “the managed death” has been appearing in American literature over the last decade. It is attached to the idea that “all of life’s problems can be reduced to the management level” where the political morals of self-determination and freedom can be used to guide decision making (Callahan, 1995, p. 227). Although death may in fact be brought back into the family arena through the advancement of palliative care ideals, it is done “under the aegis of secular self-determination” not under the auspices of a natural death (Callahan, 1995, p. 227). Callahan states that some people would argue that proponents of the palliative care approach may have been over zealous in their attempts to improve the lot of the dying. Under these auspices, a new rhetoric has developed which encompasses notions of conscious living and conscious dying, and the right of every human being to self-determination. In this climate, patients are given options and choices of how they might like to “manage” their death. These options include palliative care, suicide, euthanasia, and physician assisted suicide (Callahan, 1995).

Illich (1995) also refers to life as being “under professional management”, and explains that for some people this management began even before birth, although he does not

explain how this is the case. He also discusses the “managed postponement” of death as being a process that is lifelong; from the moment of birth, he argues, our lives have been managed by medical intervention and social policies that have dictated our existence. Within this managed environment, Illich posits that we have become disembodied beings who think of ourselves as being managed like a RAM drive on a computer. Within this discourse, he argues that it is “misplaced concreteness” in our disembodied states that renders us incapable of experiencing the reality of our frail existence, the inevitability of death, and the need to prepare for it.

Callahan (1995) argues that by embracing notions of freedom and self-determination, the managed death has become romanticised as being a natural occurrence at home among those we love, quietly and peacefully. Twenty-two years earlier, this issue was discussed by Lamerton (1973), who pointed out that although it may be ideal to care for the dying at home, it is often an onerous burden for family members who may be able to do little to relieve the physical distress associated with many illnesses (Lamerton, 1973). The managed death is, however, becoming more of a reality with an ageing population and limited health resources. Managed care may be an inevitable necessity as health funding is limited, health needs of an ageing population are increasing, and the need to measure effective expenditure is required by managerial systems of care (Schwartz & Weiner, 2003).

Maybe one of the most sensible arguments to come out of this seeming impasse between treatment and palliative care is the point at which these two philosophies of care intersect (Cohen, 2003). That is, the point where medical intervention can, in fact, aid the ill person

and their family in achieving a pain-free death with symptoms under control, choices made about place of death, and the provision of time for the individual and family to say their goodbyes. This approach would, in fact, bring us full circle to yet again encompass the ideal of death as a natural part of the life course; the dying put back into the care of their families, with death again occurring in the home (Callahan, 1995). In this context, medicine is no longer cast as the “interfering busybody”, the tool of survival at all costs, but the means of a good and pain-free death (Cohen, 2003).

2.5 Social Work and End-of-Life Care

Assisting social work clients at the end of life is becoming increasingly complex (Keigher, 2001). This is partially due to the constant shifting of boundaries between life and death in light of medical technology and its life-extending techniques (Keigher, 2001). This results in complicated discussions about decision making with social work clients. Themes in the most recent social work literature pertaining to end-of-life work include: the legalisation of life-ending measures, the use of advanced directives, end-of-life decision making, the ethical and theoretical knowledge base of social workers, the provision of quality care, and the future of health social work. These are not disparate themes and do not, therefore, yield to the arbitrary imposition of a structure that would allow for each to be considered separately. Their interconnectedness is demonstrated in the multiple research reports that are reviewed in this section.

Much of the international literature relating to social work in the health field has been heavily influenced by the current debate on legalised death. The practice of euthanasia has

been legalised in Switzerland since 1941 (Humphreys, 2005); however, this topic has received increasing attention in social work literature from the United States since the legalising of Physician Assisted Suicide (PAS) in Oregon in 1997, and the following implementation of the Death with Dignity Act in 2001 (Mackelprang & Mackelprang, 2005). The Netherlands has practised euthanasia and assisted suicide for many years, but also legalised the use of this practice by passing the Termination of Life on Request and Assisted Suicide Act in 2002. Belgium also passed a law legalising euthanasia in 2002, it is called The Belgian Act on Euthanasia (Mackelprang & Mackelprang, 2005). The passing of these three laws within the last decade reflects the increasingly common debate around euthanasia. However, many more unsuccessful attempts have been made to legalise assisted death. Euthanasia is quietly practised in Finland but there are no laws legalising it or prohibiting it, and provided the action is regarded as necessary, no legal action is taken (Humphreys, 2005). There have been eight bills presented to parliament from 1936-2003 in England and Wales but none has been passed. The Northern Territory of Australia had legal physician assisted suicide for seven months until the law was repealed in 1997. During this period Dr Phillip Nietzsche assisted four people to die (Humphreys, 2005). The situation in New Zealand is similar to many other countries where there are ongoing debates about legalised suicide and voluntary euthanasia.

According to Mitchell and Owens (2003), the illegal provision of physician assisted suicide is known to occur in many countries including New Zealand. In a national survey of GPs, it was found that at some point in their career, 88% (1100) doctors had attended a death and that 63% (693) had made decisions that could hasten death. In 5.6% (39) of cases the GP's

decision had directly contributed to the patient's death in a manner similar to the practice of euthanasia or PAS used elsewhere. In 89% (1116) of the total deaths there was a palliative care team available. This situation also raises the question of why the GP is not considered part of the palliative care team. Mitchell and Owens (2003) argue that these findings debunk the argument that euthanasia and PAS are being pursued because of a lack of palliative care services. They do suggest, however, that these findings indicate that palliative care does not meet the patients' needs. In light of these findings, they conclude that New Zealand needs to make a greater commitment to the provision of quality palliative care services, as well as reconsidering the legal framework relating to end-of-life decisions (Mitchell & Owens, 2003). Attempts have also been made to legalise euthanasia in New Zealand.

In New Zealand in 2003, the Death with Dignity Bill was presented in Parliament by Peter Brown, the Deputy Leader of New Zealand First Party. In his opening address, Brown also made the point that many people may believe that euthanasia is only considered by people when there is inadequate palliative care. He said that he did not believe this was the case; he stated "I do not see this bill as being in conflict with the hospice movement but as compatible with it" (Brown, 2003). The bill failed by 60 votes to 58, a narrow margin (Voluntary Euthanasia Society of New Zealand [VESNZ], 2008). In a 2008 survey of over 2,000 New Zealanders, it was found that 71% wanted the legal right to have an assisted death if they had a terminal illness (VESNZ, 2008). In clarifying New Zealand's legal position, the Voluntary Euthanasia Society (VESNZ) explains that passive euthanasia, the right to refuse medical intervention, is legal in New Zealand, but active euthanasia, action

that directly leads to death, is illegal. The Society states that the New Zealand *Code of Health and Disability Services Consumer's Rights* (1996) legalises the use of Advanced Directives (AD) which can be written or orally communicated (VESNZ, 2008). This topic will now be considered in light of its relation to the role of social work in end-of-life care.

In the review of the international literature on this topic, several references were found relating to the American National Association of Social Work's (NASW) 1994 definition of decision making at the end of life:

End-of-life decisions are the choices made by a person with a terminal condition regarding his or her continuing care or treatment options. These options may include aggressive treatment of the medical condition, life-sustaining treatment, palliative care, passive euthanasia, voluntary active euthanasia, or physician-assisted suicide. (p. 58)

The mention of assisting patients to assert their right to self-determination is also identified as the primary element of the NASW's policy and practice guidelines for social workers in end-of-life care (Wesley, 1996). Wesley discusses the notion of self-determination in relation to end-of-life decision making and describes it as an individual's sense of right, and sense of choice, based on their values, morals and principles. In an ongoing study being conducted in New Zealand looking at ethical decision making in social work, it was noted that issues related to self-determination were the most common ethical dilemmas facing social workers (Kane & Briggs, 2002). This point is also raised in international literature.

One of the most difficult roles faced by social workers in end-of-life work is assisting individuals and families in decision making. A study conducted in Texas by Csikai and Bass (2000) investigated social workers' views of ethical issues faced in end-of-life care. As well as exploring their use of the NASW policy on ethical decision making, the researchers considered social workers' views of practice roles in this field. The findings, firstly, highlighted issues pertaining to ethics training. They demonstrated that less than one-third of the social workers had received specific training on ethics; another third had received some exposure during training; and the remaining third had only been exposed to the NASW Code of Ethics. Secondly, the researchers found that that the NASW guidelines to assist ethical decision making were only familiar to 16 of the 56 social work participants. Thirdly, the study explored the practice roles identified by social workers. In order of importance, these were found to be: ability of patients to maintain self-determination; liaison with health care providers; support; awareness of end-of-life options; liaison between individual and family members; encouragement of involvement of family; referral to other support services; discussions about suicide; examination of own values; and discussions of issues related to life-ending measures (Csikai & Bass, 2000). These findings hold implications for the future training of health social workers, for the continuing presence of health social workers, and for the care and well-being of social workers in this field.

The training of health social workers was also raised in a study conducted in New York, by Christ and Sormanti (1999). This study indicated that training of social workers had failed to provide them with an integrated theory-practice model for application in their work. In a

similar manner to the Texas study (Csikai & Bass, 2000), the New York study also highlighted the various roles performed by social workers and suggested that there was a lack of clear definition of the tasks and function of social work (Christ & Sormanti, 1999). The authors suggested that this lack of definition was one of the barriers to the growth of health social work. Social workers in the New York study identified their practice strengths as consisting of advocacy, counselling, symptom management, and communication; the weaknesses they identified included bereavement, education, ethics, case management, decision making, and discharge planning. It is interesting to note that in both studies, decision making at the end of life was identified as an area of weakness, and liaison and advocacy were identified as strengths.

Another study, in South Carolina, also similar to the Texas study which explored social work's ethical base, by Manetta and Wells (2001), found that social workers had limited knowledge of ethics and their association's code of ethics. In fact, many social workers in the study raised views about physician assisted suicide that directly contradicted the NASW policies. Ethical guidelines are provided to assist social workers with decision making, a progressively complicated process in end-of-life care. The complex nature of decision making is reiterated in a study by Mackelprang and Mackelprang (2005).

Medical advances in the last century have led to clients and social workers facing increasingly complex decisions about treatment and intervention (Mackelprang & Mackelprang, 2005). Medical intervention is best viewed as occurring along a continuum of the following types of care: palliative-active-aggressive-invasive. Palliative care is

symptom control and comfort, not life prolonging. This level of care is provided by family and hospice. Active end-of-life care involves efforts to prolong life that are not invasive. The level of care involves the use of antibiotics and assistance with natural fluid and nutritional problems. Aggressive treatment involves artificial feeding, hydration and intravenous medication; and invasive treatment involves CPR and ventilation. The article by Mackelprang and Mackelprang (2005) focuses on decision making at the end of life as it relates to the legalisation regarding euthanasia. The issue of euthanasia was not raised in any detail by participants in this current study; therefore, I have not specifically elaborated on the myriad of views on this practice. My focus in this review of the literature is primarily on the complex role of social work. Social workers' attitudes and views are, however, discussed and debated in social work articles (Leichtentritt, 2002; Miller, Mesler, & Eggman, 2002; Ogden & Young, 2003) as are the ethics relating to this issue and social work practice (Csikai & Bass, 2000; Leichtentritt, 2002; Manetta & Wells, 2001).

The mandate of social work to do no harm may appear in conflict with death-advancing techniques and this may be contributing to the ongoing debate about the role of social workers in states where PAS is legal (Mackelprang & Mackelprang, 2005). Regardless of this apparent conflict, it is the responsibility of social workers to assist clients in expressing and gaining their rights to self-determination, even if it results in the withdrawal of life-prolonging measures and the refusal of interventions (Mackelprang & Mackelprang, 2005). For guidance and clarity about social workers' roles and responsibilities, the American NASW (2000) issued the following statement:

NASW does not take a position concerning the morality of end-of-life decisions but affirms the right of the individual to determine the level of his or her care. Social workers should be free to participate or not in assisted-suicide matters or other discussions concerning end-of-life decisions depending on their own beliefs, attitudes, and value systems. However, it is inappropriate for social workers to deliver, supply, or personally participate in the commission of an act of assisted suicide while in their professional role. At the same time, if a social worker is unable to help with the decisions about assisted suicide or other end-of-life choices, he or she has a professional obligation to refer patients and their families to other competent professionals. (p. 60)

Another research article that also discusses decision making, PAS, and end-of-life care, notes that in most American states it would be illegal for social workers to provide information about PAS as this practice is against the law (Megivern, McMillan, Enola, Striley, Cabassa, & Munson, 2007). The authors are critical of the NASW statement, which they argue does not point out the legal ramifications of such action in states where PAS is not legalised, or in states where the laws regarding PAS are ambiguous. They also argue that the NASW statement does not provide enough guidance for social workers about when they should become involved, for how long, and under what circumstances. The research conducted by Megivern et al. (2007) explored the quality of care being provided by social workers in South Carolina, a state where the laws relating to PAS are ambiguous.

Megivern et al. (2007) explain that the provision of competent care is multidimensional and requires the combination of social workers' skills, such as cultural competence, interpersonal skills, and technical knowledge. These skills need to be delivered in a sensitive manner in consideration of ethical codes of practice and knowledgeable practice skills. However, if a social worker has the prerequisite skills but is working within a constrained model of care provision or within an agency without the necessary

infrastructure, or lacks support from colleagues and advisors, they may struggle to provide quality services for their clients. The authors encourage social workers to challenge social work systems of care in order to bring about transformation of services and improved quality of care (Megivern et al. 2007). In order for social workers to be competent practitioners in the increasingly complex health field, they will need access to multi-disciplinary resources, and ongoing knowledge development relating to the specifics of medical illness and interventions (Wheeler, 2007). The exact nature of social work, including social workers' roles, also requires consideration and clarification.

The major roles of health social work are: advocate, counsellor, team member, and context interpreters (Bern-Klug, Gessert, & Forbes, 2001). Context interpreters provide interpretation of medical jargon, information relating to specific illnesses, the range of treatment options, prognosis, and other medical decisions that people are likely to face and that can be difficult without help. Social workers are able to assist the individual and family in this process and provide support as they come to terms with the emotional upheaval often faced by people dealing with life-threatening illness (Bern-Klug et al., 2001). It is important that the individual, family, and care team all understand the nature of the medical prognosis as this contributes to the development of an integrated care plan and preparedness for death.

As background research for my study, I conducted a number of interviews with social workers currently employed in New Zealand hospices. In one such interview, I was given a sheet of paper that had been prepared by the social worker, outlining her roles within the

hospice. She noted that social work role consists of “Talking with families about funding, resources and placements in private hospitals” (J. Tan, personal communication, October 20, 2005). Thus talking may include helping individuals and families negotiate other large systems such as Work and Income New Zealand (WINZ), supporting people to gain access to funding and other resources, mediation, advocacy, crisis intervention, community networking, social support, community visits, interdisciplinary meetings, consultation, and promotion of policies to support social development (J. Tan, personal communication, October 20, 2005). Regardless of the vital role being provided by hospice social workers, the role of social work does not appear to be well understood in the community. North Island social workers made a submission to a local district health board (DHB) palliative care district working party that had not consulted them, and outlined the role and function of social work to demonstrate the pivotal role of social workers in palliative care. The submission highlights the various functions performed by social work services in providing care coordination, discharge planning, assisting individuals and families with decision making and counselling, and liaison with a multitude of community support agencies (Workers, 2005).

The role of social workers as key players in end-of-life care was also confirmed at the *Social Work Summit on End-of-Life and Palliative Care* held in 2002 in America. The key goals from this summit were to improve care for the dying and their families by proving a collaborative approach to care, education, training, research, and policy within the profession (Durham, 2002). Although it is undeniable that there is a vital role performed by social workers in end-of-life care, there appear to be some barriers to their involvement.

Reese and Sontag (2001) explain that 17 years after the introduction of social work services in American hospices there is still resistance to their presence. They suggest that some of this resistance is based on social workers' and other health professionals' lack of understanding of the role and function of social work in hospice. The primary factors contributing to a lack of collaboration between health professionals are: lack of knowledge of interdisciplinary areas of expertise; role blurring; contrasting values of the individual workers or value differences between disciplines; theoretical differences; power play; scapegoating; non-team players; client stereotyping; and administrative differences. In relation to theoretical differences, the authors provide an example of conflict that can arise when other professions, who may be used to medical models, encounter the ecological systems perspective often used in social work. The ecological systems perspective is discussed in more detail in Chapter Three (see section 3.6.4). The different approaches from different disciplines to end-of-life care may be contributing to the variation in services that are provided.

The editors of a report by the European Society for Medical Oncology note that although there is a high level of consensus amongst health professionals regarding the importance of palliative support, there are wide variations in the provision of such services. This results in higher levels of distress, a lack of service coordination, and patients being unprepared for death (Cherry, Catane, & Kosmidis, 2003). In advocating social work's role in this field, Mackelprang and Mackelprang (2005) argue that social workers can ensure that a broader perspective is taken in decision making at the end of life, rather than a narrow view of medical issues only. The authors also raise the argument that if the environment in which

people are living is improved, quality of life will be improved and people may then want to live longer. Care that is provided needs to meet the needs of those receiving it. It is suggested that the use of advance directives (AD) can provide a structured approach to the consideration of the spiritual, emotional, and social factors at the end of life (Black, 2005a; Lambert, McColl, Gilbert, Wong, Murray, & Shortt, 2005; P. Miller, 2007; Rurup, Onwuteaka, Bregje, van der Heide, van der Wal, & Deeg, 2006; Zapka, Carter, Carter, Hennessy, & Kurent, 2007).

Black (2005b) examined social workers' attitudes and experiences relating to death and whether these factors had any influence on their communication about advance directives. Within this research, communication processes were identified as consisting of seven phases. These are:

. . . (1) initiation of the topic, (2) disclosure of information, (3) identification of a surrogate decision-maker, (4) discussion of treatment options, (5) elicitation of patient values, (6) interaction with family members and significant others; and (7) collaboration with other health care professionals. (p. 43)

The use of advance directives is also discussed by Aikman, Thiel, Martin, and Sinclair (1999) who found that the advance directive was an effective decision-making tool for people facing the end of life. The majority of participants indicated in their advance directive that they did not want their life to be extended by artificial life support if they were seriously ill (Aikman et al., 1999). Research also indicates that clients prefer to speak to a social worker about their end-of-life decisions than to any other health professional (Osman & Perlin, 1994).

In another study investigating the decision-making processes of an elderly population, it was found that advance directives were completed by drawing more on life experiences than on knowledge from health professionals (Lambert et al., 2005). The older population studied also considered spirituality as the primary factor in decisions regarding health. The researchers indicated in their findings that because decision making was based on the rich life experiences of the participants, it was not a structured linear process, but a uniquely personal process for each person (Lambert et al., 2005). As well as noting differences in the way that older people make decisions about the end of life, research highlights cultural issues, albeit primarily ethnic differences, in decision making related to end-of-life issues. A review of 33 empirical studies on decision making among non-white ethnic groups revealed limited knowledge of advanced directives and variations in decision-making preferences (Kwack & Haley, 2005). End-of-life practice and policies need to be developed so that they promote all peoples' right to have choices, and do not contain any discrimination based on age, colour, ethnicity, religion, socioeconomic status, and sexual identity. Social workers are, therefore, called on to challenge injustices when they see them occurring (Mackelprang & Mackelprang, 2005).

2.6 Conclusion

The major themes explored in the literature review provide a glimpse of the wealth of information that is currently available about various aspects of palliative care. The bulk of this literature concerns cancer patients, and it is noted that there is a clear lack of research on people dying of diseases other than cancer. It is also noted that there is a lack of research in which terminally-ill people participated, and this is attributed in part to practical and

ethical issues (Fordham & Dowrick, 1999; Scott, 1999). The topic of quality of life is covered by a range of research articles; in particular, it is noted that many of the studies appeared to be using flawed research tools, resulting in a certain amount of uncertainty about the findings. Communication between professional health carers and patients is discussed in conjunction with the topics of: diagnosis, individual differences in disclosure, cross-cultural views, decision making, preparedness for death and bereavement, diagnosing dying, and optimism. The issues relating to intervention and palliative care that are currently being energetically debated in the literature have been reviewed by considering power dynamics, the medicalisation of dying, avoidance of death, and the management of death.

In the second half of the literature review, I have paid particular attention to the issues relating to the increasingly complex role and practice of social work in end-of-life care. In particular, I have noted the interconnectedness of literature relating to end-of-life decision making, and the valuable contribution of social work practice in this field. It is also noted, however, that as a discipline we have more work to do in clarifying our role and function in the health field. This requires an ongoing commitment to education, specialised training, and action.

In Chapter Three, I will discuss the use of theory in social work practice, and, in particular, theories that provide a contextual view of the issues raised in the literature review. Attention will also be given to specific theoretical lenses that can be used to comprehend the diverse experiences of social work clients experiencing loss and grief.

Chapter Three

Theory

Theories are constructed by persons whose historical and cultural situation is revealed in the sorts of phenomena they choose to theorize about. (Joralemon, 1999, p. 32)

3.1 Introduction

The fundamental aim of this thesis is to explore individuals' and families' experiences of palliative care and dying in Aotearoa New Zealand, whilst also considering the role culture plays in this journey. Attempting to comprehend the multifaceted experiences of the participants, within multiple environments, suggests the use of an ethnographic research methodology. The use of a qualitative research methodology and, in particular, ethnography, is discussed further in the methodology chapter, Chapter Four. Collecting a wide range of data relating to interpersonal experiences, intrafamilial experiences, and the embeddedness of these experiences in the private and public spheres, resulted in the need for a broad theoretical lens with which to view the data and the findings. The ecological perspective, combined with psychosocial theories of loss and grief, offers such a view as it allows for consideration of a wide range of issues from the micro experiences of the individual, to the broader (macro) social context.

3.2 Structure of This Chapter

This theoretical discussion begins by considering social work's unique focus on the person and the environment. The research topic is then linked to theories of social development, including ecological theory. Consideration is also given to the use of the ecological

perspective in social work as a metatheory within which other theories are placed. I will briefly consider the use of ecological theory in medical anthropology, as its application within this discipline further highlights the role of culture and environment, both aspects of this thesis. I will then present a range of grief theories relevant to the research topic of death and dying. Particular attention will be paid to Stroebe and Schut's (2001) dual process model (DPM) and its consideration within an ecological framework. The dual process model has already been shown to provide an effective orientation for social workers in palliative care (Beresford, Adshed, & Croft, 2007). Links will also be made in this section between theory, the discipline of social work, the thesis topic, and the health field, which provides the context for the current study.

3.3 What Is Theory and What Does It Do?

Before I launch into a descriptive account of social work theories, I want to first consider the use of theory in social work practice. I admit to having been somewhat perplexed about the nature of theory in my undergraduate years when learning about the epistemology of social work practice. Our school tended to lean towards a postmodern interpretation of theory and undergraduates were introduced to strengths and empowerment perspectives, radical and anti-oppressive practice, humanistic and radical theories, task-centred approaches, and systems theories such as ecological theory (Payne, 1997).

These theories are reflexive in nature and consider the individual within the context of a complex, ever-changing environment. By contrast, modern or positivist views of theory represent the strict application of the scientific method, providing information that can be

validated (Payne, 1997). Postmodernist views of theory are more inclusive and incorporate models, perspectives, and theory. A perspective does not tend to provide a prescriptive approach to social work, it does, however, contribute significant and fundamental ideas to practice. A model tends to provide a framework of how to practise social work, but it is impotent unless it contains a strong theoretical base. Therefore, Payne (1997) argues, a comprehensive social work theory would also contain all three of these elements: theory, model, and perspective. A fairly flexible definition of theory is also provided by Kottack (2002), who states: “An explanatory framework, containing a series of statements, that helps us understand why (something exists); theories suggest patterns, connections, and relationships that may be confirmed by new research” (p. 708). New research can provide feedback, which is instrumental in bringing about reflexive developments in the theory, thus contributing to theoretical evolution (Kottack, 2002).

3.4 Theory and Social Work

Social work’s unique contribution to the field of practice is its focus on mediating the fit between the person and the environment. The following definition is provided by the International Federation of Social Work (as cited in Aotearoa New Zealand Association of Social Workers [ANZASW] (2001):

The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. 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.

Transactions between people and their environment can be complex, requiring a strong epistemological base for practice. This knowledge base is derived from research and evidence-based practice and applied in a diverse range of settings. Awareness of, and attention to, indigenous knowledge is also required. For this reason, the Aotearoa New Zealand Association of Social Workers (ANZASW) has also developed a bicultural code of practice. The application of knowledge requires a comprehensive understanding of the theory base of social work. This eclectic knowledge is acquired from theories of social systems, human development, multicultural and bicultural perspectives, and theories of behaviour change (ANZASW, 2001).

3.5 Integrated Theories

An integrated framework for the practice of social work is provided by Nash, O'Donoghue, and O'Donoghue, Nash and Munford (2005). Within this framework, theory is developed from practice and evolves as a result of knowledge being gained and assimilated. Once the theory is adapted to incorporate this new knowledge, it can better inform practice. This process of reciprocity allows for the development of sound theoretical models for the specific purpose of social work. The authors provide an integrated model combining attachment theory, strengths-based theory, community development, and the ecological perspective. They suggest that as new information emerges, as we gain more information through research and practice, and as wider social and political climates change, social work theory also needs to change if it is to remain relevant and applicable (O'Donoghue et al., 2005). A similar approach of combining theory is used within this thesis to provide a

way of understanding the participants' journeys from diagnosis to death. The two types of theory drawn on are ecological systems theory, and theories of loss and grief.

3.6 The Ecological Perspective: A Metatheory for Social Work Practice

A review of the evolution of ecological systems theory is provided by O'Donoghue and Maidment (2005). The authors explain that ecological systems theory, which is a combination of systems and ecological theory, has been referred to as a "metatheory" by Mattaini and Meyer (2002). Systems theory, the theory of ecology, and the resultant ecological perspective have contributed significantly towards the underlying metatheoretical base of social work. These theories developed at a time when social work was in need of comprehensive contextual theory that could contribute to its foundational framework (O'Donoghue & Maidment, 2005). The ecological framework has been promoted in a range of social work texts (Gambrill, 1997; Munford & Nash, 1994; Payne, 1997; Pincus & Minahan, 1973), and has been adapted to incorporate and reflect the nature of social work in increasingly complex environments and situations (O'Donoghue et al., 2005; Nilsson, 2007; Ungar, 2002). By conducting a comparison of New Zealand and Australian social work literature, O'Donoghue and Maidment (2005) found that the ecological perspective was more commonly used in New Zealand than in Australia. They suggest that this could be an enduring result of the "integrated framework practice" taught in the first university-based training course at Massey University in New Zealand. The framework that was taught was based on Bronfenbrenner's (1979) ecological theory, and was readily embraced as a contextual theory in that it provided a more holistic view of human development.

3.6.1 Ecological “theory”

According to Bronfenbrenner (1986), ecological theory proposes that there are numerous interacting systems within a person’s environment. These systems represent the sociocultural context of a person’s life and consist of embedded systems within which the individual is located. The individual is located at the centre of the systems within the microsystem and is surrounded by the remaining systems: mesosystem, exosystem, macrosystem, and the chronosystem. The most intimate transactions occur in the more immediate inner microsystems. The larger macrosystems represent the cultural milieu in which the individual is embedded. All of these systems are considered in light of the chronosystem, which involves sociohistorical time and transitions during the life course (Bronfenbrenner, 1986). Bronfenbrenner’s (1979) ecological theory in combination with systems theory form the basis of Germain’s (1991) work on human behaviour. It is this flexible use of ecological theory that contributes to its adaptation and application within varying disciplines.

3.6.2 Ecological theory, the health field, and medical anthropology

According to Joralemon (1999), the use of ecological theory in health is widely accepted in the field of medical anthropology. “Medical anthropology theory is a blend of social science, epidemiological, and biological perspectives on disease” (p. 31). A theory attempts to define a particular recurring pattern that is considered to be predictable; theories are used to reduce information to certain variables of interest to the researcher. Joralemon (1999) provides the following example:

Newton did not need to know the color of the apple that fell on his head to derive his theory of gravity. However, the color of the apple that Eve offered to Adam in the Bible's Genesis story might make a significant difference to a theory of color symbolism. Any theory must identify which characteristics are considered relevant and which evidence will be accepted. (p. 31)

The acceptance of ecological theory in medical anthropology was spearheaded by the work of Alland (1970), who argued that human adaptive abilities were either enhanced or constrained by their environment. He outlined three types of adaptation: genetic, physiological, and cultural. Genetic adaptation is regarded in terms of evolutionary theory and the theory of natural selection. Physiological adaptation describes humans' ability to biologically adapt to harsh environments. Cultural adaptation describes humans' ability to adapt to the environment through the use of culturally derived responses. Alland explained that it is through the use of culturally developed responses to the environment that humans have learned to survive against threats. Culturally derived survival mechanisms can be expressed as behaviours (change in the person) or as geographic experiences (change in the environment) (Joralemon, 1999). The epistemology of medical anthropology, applied in health research, can provide insights into behaviour and meaning; it can also highlight implications for practice and make practical contributions to clinical work (Carmona, 2002).

3.6.3 Ecological theory and social work

O'Donoghue and Maidment (2005) identify an article by Vickery (1974) as the first to incorporate systems theory into social work practice. Two years later, Gitterman and Germain (1976) published an article called "Social work practice: A life model". This

article was a precursor to their book: *The Life Model of Social Work Practice*, which was published in 1980. These authors provide an overview of the concepts of ecological thinking. The first, and most central, concept of ecological theory is adaptation. Adaptation is an active, as opposed to passive, process which improves the person/environment fit. This “goodness of fit” is achieved by balancing the individual’s resources, needs, desires, goals and abilities with the quality of the environment. Germain (1991) suggests that adaptation is a result of coping mechanisms being triggered by an outside stressor. The role of environmental stressors on physical and psychological well-being is explored by T. Miller (2007) who argues that a global perspective is required to address the myriad of influences on health and well-being. He suggests that approaches to intervention need to occur on the psychological, environmental, and social levels if they are to succeed. This is a common approach in the ecological perspective. The second concept within the ecological model is stress.

Stress can occur as a result of life experiences, but it is also subjective in that the same type of stress can be experienced differently. What constitutes extreme stress for one person may not constitute extreme stress for another. The factors that contribute to this situation are culture, experience, resources, gender, and personal characteristics. For example, the Kwahu people in Ghana who have reached old age do not consider the contemplation of death as stressful; they consider it as a welcome friend (van der Geest, 2002). By contrast, research conducted by Howarth (1998) in North London found two opposing views to death and dying. Two themes emerged from interviews with 72 people over 75 years of age. The first theme was “readiness for a welcome death”, and the second theme was

clinging “fiercely to life” (Howarth, 1998, p. 677). The difference between the two groups appeared to be quality of life and those who welcomed death had clear ideas about what constituted a good death: a timely, quick, painless death for which they were prepared.

Howarth (1998) found that in a modern culture with access to medical life-prolonging techniques, death was not viewed by many in the London group as natural or desirable. He also found that many of the widows who were interviewed talked about the death of their spouse as stressful, painful, and arduous. This research highlighted the response to illness in modern societies: life-prolonging medical intervention (Howarth, 1998). The two studies, one from Ghana, the other from London, demonstrate the nature of subjective stress, when considering the same situation—death in old age. The way in which people respond to the situation, and interpret the situation, will vary depending on the perception of the event and the cultural context in which it occurs (Germain, 1991). Germain suggests that it is useful to consider adaptation to stress along a continuum from positive adaptive coping to negative maladaptive defence. The transactional nature of these concepts allows for intervention at the interface of the person and the environment.

3.6.4 Limitations and strengths of the ecological perspective

The development of the ecological perspective in the 1950s and '60s provided social workers with a broad conceptual framework which was more suitable to their profession than the individualised psychoanalytical models of the time (Ungar, 2002). However, early adaptations of the ecological perspective did not take the position of the observer into account. For example, when applied to social work practice, there is no acknowledgement

of the power dynamics between the client and the social worker. The central concept of the theory—adaptation—implies that there are particular norms to be achieved in the process of adapting. In the process of assisting clients to “adapt”, social workers may have naively been using their power to maintain the status quo, a particular societal standard of behaviour. Ungar (2002) explains that there was no deconstruction of “the standpoints of those who decide which adaptations are determined to be the best” (p. 481). O’Donoghue and Maidment (2005, p. 44) also note that one of the deficiencies of the ecological perspective is that it does not account for “power, oppression and marginalization”. Despite its shortcomings, the ecological theory is drawn on by a number of disciplines, such as medical anthropology.

3.6.5 Ecological theory, loss and grief

Drawing on the ecological perspective as a metatheoretical base, theories of social work have been adapted to the various environments in which practice occurs. Of particular interest in the line of enquiry taken in this thesis are theories that can be applied in health social work and, in particular, the sub-field of palliative care. The theories of particular relevance are those based on studies of loss and grief. The development of these theories will now be explored, as will their use in social work practice.

3.7 Theories of Loss, Grief, and Adaptation

Grief was identified as a “definite syndrome” in a classic article by Lindemann in 1944 (as cited in Doka, 1989). It has also been considered as an evolutionary process (Archer, 1999, 2001); a stage (Kubler-Ross, 1969); a series of tasks to be completed (Worden, 1991); and

a complex process (Folkman, 1997, 2001; Stroebe & Schut, 1995, 2001). The manifestations of grief identified by Lindemann (1944) consisted of: preoccupation with the lost person/object, somatic distress, feelings of guilt, hostility towards others, and a breakdown in the usual patterns of functioning. These symptoms have been explored and elaborated on in numerous studies exploring the nature of grief (Parkes, 1975; Raphael, 1984; Scrutton, 1995; Volkan, 1970; Worden, 1991). Although Lindemann's conceptualisation of grief is still considered fairly accurate to this day (Stroebe & Schut, 2001), there has also been greater consideration of the adaptive processes that occur during grieving. Germain's (1991) conceptualisation of adaptation consists of two processes that act as precursors to adaptation: stress and coping.

Lazarus and Folkman (1984, p. 565) define coping as "the changing thoughts and acts that an individual uses to manage the external or internal demands of stressful situations". Coping is regarded as a complex process which begins when an individual perceives a threat or change in their environment (Folkman, 2001). Lazarus and Folkman's (1984) theory of coping as a mediator of emotion is a cognitive-motivational-relational theory. It is cognitive in that it requires knowledge and appraisal of the situation; motivational in that it requires appraisal of the individual's ability to do something about the situation; and relational in that it results in a change in the person/environment interaction (Nilsson, 2007). As each individual has different values, morals, and resources, they will appraise the change or threat differently. The first appraisal of such a threat, referred to as "primary appraisal", relates to perceived personal threat. Secondary appraisal of the individual's coping resources then occurs. Used in conjunction, these appraisal processes will determine

the level of emotion experienced by the individual (Folkman, 2001). When a change occurs in the situation as a result of appraisal, the person then engages in further appraisal and coping responses (Folkman, 2001). Lazarus and Folkman (1984) and Folkman (1997) explain that problem-focused coping is an attempt to manage the problem, while emotion-focused coping is an attempt to regulate the emotions associated with the event. Engagement in these two coping responses leads to either a favourable resolution or an unfavourable or no resolution. Favourable resolution then results in positive emotion and the resolution of the perceived threat. Unfavourable resolution or no resolution results in distress, which leads to further reappraisal of the situation (Folkman, 1997).

Findings of research studies conducted by Folkman and others indicate that although people can be in stressful situations, where there may not be any favourable resolution available, they can still achieve a positive affect (Folkman, 2001). Folkman's 2001 study was conducted with caregivers whose partners had AIDS. Findings of his 1997 study indicated that caregivers' engagement in active problem-focused coping led to less negative mood, and an increase in positive mood. The increase in positive mood was attributed to a greater sense of control and mastery experienced by the caregivers as they were able to resolve or manage the daily tasks of care-giving (Folkman, 2001). These findings led to a revision of Lazarus and Folkman's 1984 model and the addition of another process: whereas an unfavourable resolution or no resolution was understood to lead to distress in the former model, unfavourable or no resolution could, in fact, lead to no distress or to meaning-based coping. Engagement in meaning-based coping led to positive emotion and a sustained coping process. These processes were then linked into the rest of the model,

suggesting that reappraisal of the situation can occur at any time, or multiple times, and can result in different outcomes (Folkman, 2001). This model significantly informed the development of Nilsson's comprehensive model for social work practice (Nilsson, 2007).

3.8 A Comprehensive Model for Social Work Practice

Nilsson (2007) has proposed a theoretical framework to explain the process of adjustment that is required when an individual and family are informed of a health condition, or require hospitalisation. He argues that in order for social workers to assist people using adjustment-related interventions they require a comprehensive theoretical framework to guide them. Nilsson has drawn on the theoretical underpinnings of Lazarus and Folkman's (1984) theory of coping as a mediator of emotion, Folkman's (1997) later adjustment to this theory, and McCubbin, Thompson, and McCubbin's (1996) work on systems theory. Nilsson (2007) argues that Folkman's (1997) addition of meaning-based coping provides a model that is congruent with the perspective of adjustment held by social workers in the health field. He describes this as the "crucial role of appraisal processes" (Nilsson, 2007, pp. 16-17), and suggests further modification to the coping process at this point in the model. Nilsson's primary modification is the incorporation of McCubbin and McCubbin's (1996) "concepts of 'family resources,' and 'family situational appraisal' (including 'family schema,' 'family coherence,' and 'family paradigms') within the *appraisal* process" (Nilsson, 2007, p. 17). The incorporation of family systems concepts provides an eco-systems perspective rather than the previous psychological approach. This comprehensive model can be used by social workers to explain and conceptualise their understanding of the theoretical process of adjustment (Nilsson, 2007).

Nilsson's (2007) use of these theories demonstrates their intrinsic value in the development of the ecological perspective, and their contribution to the construction of social work theories applicable to the health field. He argues that social work as a profession has struggled in its attempts to adequately link theory and practice. Within the health field, the future of social workers may depend on their ability to articulate their practice, and demonstrate its efficacy. Nilsson cites financial pressures within the health field, the ageing population, increasing expectations in a technologically advanced society, and outcome-focused health care as bringing these pressures to bear. He explains:

The (Australian) National Allied Health Casemix Committee (NAHCC) has accordingly attempted to address these issues, in part, through the development of a classification model to describe the reasons for allied health intervention (Indicators for Intervention-IFIs) that will form the basis for later development of Performance Indicators (PIs). (p. 2)

In a study conducted in two Australian hospitals in 2002, where he interviewed 18 experienced social workers, Nilsson (2007) explains that he explored understandings of two IFIs, "Adjustment to Health Condition and Adjustment to Hospitalisation". One component of this exploration was to discover what theories underpinned social workers' conceptualizations of these two IFI. Findings of this study indicated that there were similarities in how the participants understood "adjustment" and the theories that informed their understanding. Nilsson states:

All participants included the concepts of *coping* (or *managing*), *emotions*, *subjective meaning*, *adaptation* (or *integration*), and *support* within their discussion. Most participants also identified a very similar range of theories as underpinning this concept including those of *systems* or *ecological theory*, *grief and loss*, *crisis theory*, and *support theory*. (p. 7)

Although Nilsson states that “most” of the participants were able to identify the theoretical base of their understanding, he also points out that six participants were unsure about the theories that informed their understanding and two were unable to name any theory. That is eight out of a total of 18 social workers who were unable to adequately articulate a theoretical base for their practice. He also notes that the two most commonly mentioned concepts were coping and emotion (Nilsson, 2007). Lazarus and Folkman’s (1984) model, which incorporates these concepts, is also referred to by Stroebe and Schut (2001).

3.9 Development of the Dual Process Model (DPM)

Drawing on the concepts of emotion-focused coping and problem-focused coping proposed by Lazarus and Folkman (1984), Stroebe and Schut (2001) suggest each coping strategy is suitable in different circumstances. Emotion-focused coping is best used when there is nothing that can be done to restore the loss being felt; for example, when someone dies. Problem-focused coping is best used when something can be done to improve the situation, such as moving to a smaller house that is less expensive to maintain, a situation often encountered following the death of a spouse. These are both attempts at coping with an internal or external stressor. Stroebe and Schut (1995) also developed a model of loss, which provides an interactive explanation of how these two coping processes occur. Stroebe and Schut’s model varies from many of the other theories of loss and grief in that it does not provide a view of grief as a linear process (Howarth, 2007). Instead, it views grief as a more complex process of engagement in coping strategies that assist a person in adjusting to bereavement (Howarth, 2007).

The dual process model of loss was first presented by Stroebe and Schut at a conference in the UK in 1995 (Stroebe & Schut, 1995). In a later article, Stroebe and Schut (2001) elaborated on their original model. The model, currently referred to as the Dual Process Model (DPM) is described by the authors as an integration of several ideas and theories of coping with bereavement and grief.

Within the dual process model, consideration is given to two primary forms of stress, those that are loss-oriented and those that are restoration-oriented. “Loss-orientation refers to the bereaved person’s concentration on and processing of some aspect of the loss experience itself” (Stroebe & Schut, 2001, p. 395). Examples of loss-oriented approaches to grieving are Bowlby’s (1969) attachment theory, whereby the bereaved needs to let go of attachment to what was lost, and Lindemann’s concept of grief work, wherein it is regarded as necessary for the grieving person to work through their loss (Howarth, 2007). Worden’s (1991, pp. 10) first two tasks of grieving could also be considered as loss-orientated: “To accept the reality of the loss To work through to the pain of grief.” Stroebe and Schut (2001) state: “Restoration-orientation refers to the focus on secondary stressors that are also consequences of bereavement” (p. 395). An example of restoration-oriented processes of grieving can be found in the final two tasks of Worden’s (1991) “Tasks of mourning”. These are: “To emotionally relocate the deceased and move on with life” and “To adjust to an environment in which the deceased is missing” (Worden, 2002, pp. 32 & 35). In the dual process model, there is consideration of the oscillation between the two orientations (Stroebe & Schut, 2001). Stroebe and Schut propose that there will be times when people are able to confront aspects of their grief and times when they will want to avoid them.

Adaptive coping is described as an individual's actions or thought processes that attempt to regulate the negative consequences of a stressful person/environment transaction (Stroebe & Schut, 2001). In the literature on grief, it was originally argued that it was necessary for people to work through their grief, and experience the associated feelings of distress, in order to let go of their grief and accept the loss (Kubler-Ross, 1969; Parkes, 1986; Worden, 1991). This is referred to as the "myth of coping" by Wortman and Silver (2001). There are popular assumptions about grieving in Western countries that depict this process as a distressing time which is devoid of all positive emotion (Wortman & Silver, 2001). However, Nolen-Hoeksema (2001) explain that it has been demonstrated that if an individual becomes overly focused on their grief and engages in lengthy periods of rumination about the loss they are experiencing, it is more likely they will experience depression. They cite studies which have indicated that attempting to solve a problem by focusing on the problem, is an ineffective coping strategy that reduces the individual's ability to problem solve. Similarly, suppression of distress may also be maladaptive if it is persistent. Both of these responses, rumination and suppression, may be maladaptive extremes of Stroebe and Schut's loss-orientation and restoration-orientation (Nolen-Hoeksema, 2001).

Archer (1999) considers manifestations of grief as natural evolutionary processes that occur as a result of loss of attachment. Within this paradigm, grief is considered a universal experience that manifests differently depending on the closeness of the relationship between the deceased and the bereaved. The question of whether grief is adaptive is further addressed by Archer (2001), who concludes that grief is, in fact, a maladaptive response to

loss. However, he also argues that grief is a consequence of attachment, and is an innate adaptive survival mechanism. Bowlby (1969) would suggest grief is adaptive as it results in searching, calling, and trying to find that which is lost. This searching behaviour is not permanent so the searching activities and the drive to engage in them have an adaptive function. If the lost object is not found, grieving behaviour eventually extinguishes. Archer (1999) points out that the limitation of an evolutionary explanation is that it is unable to account for the individual variations in grief. Two of the variations he mentions are the nature of the social environment and the individual's coping abilities. Archer explored evolutionary theories to explain the ongoing persistence of grieving processes in animals and humans. He was unable to find an adaptive mechanism to account for the behaviour (Archer, 1999). Considering the adaptive function of grieving also intrigued Stroebe and Schut (1999) when they were developing their original theory of loss. Their later addition to their theory (Stroebe & Schut, 2001) was provided in light of research, such as Folkman's (1997, 2001) that found positive emotions could exist during the grief process; Nolen-Hoeksema's (2001) that indicated that rumination may be maladaptive; and Bonanno and Kaltman's (1999) that indicated that the minimisation of negative emotions fostered positive emotions.

3.9.1 Adjustments to the dual process model

The integration of "meaning states" was the primary adjustment to the dual process model (Stroebe & Schut, 2001). Stroebe and Schut argue that positive and negative meaning states occur as a result of loss-oriented and restoration-oriented attempts at coping. Therefore, as well as oscillating between loss and restoration orientations, people are also seen to follow

different pathways within each type of orientation. These different pathways are the same in both types of orientation and exist of “positive meaning construction” and “negative meaning construction” (p. 397). The oscillation between meaning states, and the oscillation between loss and restoration orientations can lead to adaptive coping (Stroebe & Schut, 2001).

Stroebe and Schut explain that the dual process model is an intra-personal, as opposed to an inter-personal framework, for understanding grief and bereavement. They suggest, however, that the model can be easily applied to different groups of people to explain differences in grieving styles. For example, they suggest that there may be cultural and gender differences in the amount of time spent in either loss or restoration orientations. The authors also acknowledge that people do not grieve in isolation, and that family members will oscillate between the two orientations at different times, which can result in conflict. The authors do not mention any other environmental factors that may contribute to differences in grieving styles (Stroebe & Schut, 2001). Consideration of this model in light of environmental transactions and factors could be useful in developing a framework for social work practice.

Applying an ecological framework in conjunction with theories of loss and grief would encourage the exploration of environmental factors on the process of loss and grief, death and dying. For example, Folkman (2001) found that there was a complex relationship between spirituality and positive affect in a study conducted with the caregivers of men with AIDS. The men had been recently bereaved, and qualitative exploration of the

spiritual and religious ways in which they derived existential meaning was reported as increasing positive affect. However, quantitative measures reported a corresponding increase in levels of distress. In attempting to understand this finding, Folkman considered another study conducted by McIntosh, Silver, and Wortman (1993). This study was on Sudden Infant Death Syndrome (SIDS) and also found a complex relationship between emotional states and religious beliefs. Folkman concluded that this finding is due to the fact that spiritual and religious approaches to grieving encourage people to be in touch with the loss whilst also providing comfort and hope. Folkman (2001) suggests that the comfort experienced contributes, in the long run, to people's adaptation. Applying an ecological/grief framework would highlight this complex interaction of personal and environmental transactions so they could be more fully explored and understood. The same result can be obtained by considering the dual process model within the framework of the ecological model.

The dual process model has also been discussed in relation to the findings of a study with palliative care service users conducted by Beresford et al. (2007). The study was conducted over three years, and information was collected about a number of domains. Of interest to the discussion on theory, however, are the findings about theory and practice. The researchers explored the theoretical underpinnings of the approaches taken by social workers as they were reported by service users. The service users did not identify any particular theory; however, they commented that the social workers normalised their feelings, regardless of how they felt. They explained that the social workers were able to help them understand that grief often varied. Expressions of grief were not considered

pathological, and a lack of expression was not frowned upon. The service users reported that as well as providing emotional support, the social workers helped them make adjustments within their environment and provided guidance for the family members. The researchers concluded that although no specific theory was mentioned, the actions the social workers took were congruent with certain theories of loss and grief, as well as taking the wider social issues into account. The authors concluded that one of the influential models that the social workers were drawing on was most likely the dual process model (Beresford et al., 2007).

3.10 Conclusion

Social workers are familiar with an ecological systems perspective which provides a complex interactive view of the multiple levels from which a problem can be considered (Hernandez & Jozefowicz, 2008). The ecological perspective has been used in social work literature to identify risk factors (Hernandez & Jozefowicz, 2008; Jafee & Perloff, 2003), to understand practice (Allan-Meares & Lane, 1987; Germain, 1991; Germain & Gitterman, 1980; Meyer, 1983; Nilsson, 2007; Ungar, 2002), and to conceptualise the nature of social work as a profession at the person/environment interface (Compton & Galaway, 1994; O'Donoghue et al., 2005).

The ecological perspective has been described as a metatheory (O'Donoghue & Maidment, 2005) against which other theories can be considered and within which they may be incorporated. Grief has been considered as an evolutionary process (Archer, 1999, 2001); a stage (Kubler-Ross, 1969); a series of tasks to be completed (Worden, 1991); and a

complex process (Folkman, 2001; Stroebe & Schut, 2001). It is only by combining a transactional systems perspective with loss and grief models and theories, such as Lazarus and Folkman's (1984) and Folkman's (1997) theory of coping as a mediator, and Stroebe and Schut's (1995, 2001) dual process model, that we will achieve a reflexive theoretical base from which to understand the complex multilayered, multisystemic experience of grief and its manifestations in the context of palliative care.

Theory provides explanations of why things appear the way they do, how they are connected or related to other things, and how we can explore them further (Kottack, 2002). Theory helps us determine what to pay attention to and what is unimportant, depending on the topic of concern (Carmona, 2002). An important component of a theory is reflexivity, the ability to evolve in light of new information. Theory is utilised in social work practice, policy and research, to mediate the person/environment fit, to provide a disciplinary identity for social workers, and to contribute to the construction of social work practice. Social work consists of transactions between the worker, the client, and the environment, which result in the creation of possibilities for reflexive change.

In considering the research topic of death and dying, a developmental approach needs to be considered to establish an appropriate theory that would aid understanding of social work research at the end of life. The developmental theory with the greatest utility when considering the person in the context of their environment is ecological theory. The use of the ecological perspective in social work is widely accepted as it offers a comprehensive metatheoretical framework for understanding person/environment transactions. It also

allows consideration of the multiple systems in which individuals and families are embedded. The application of ecological theory, and its corresponding concepts, is also seen in research conducted in the field of medical anthropology (Alland, 1970; Joralemon, 1999). The limitations of ecological theory are widely recognised. However, the perceived limitations of the ecological perspective can be countered by drawing on it as a metatheory, a broad background against which contemporary theories can be considered. Such approaches are commonly suggested in the development of specific social work theories (McBeath & Webb, 2002; O'Donoghue et al., 2005; Nilsson, 2007). The enduring strength of the ecological systems framework is its provision of a holistic contextual view of individuals within the social environment. The ongoing use of ecological frameworks in research and practice articles is testament to the efficacy of this paradigm (Hernandez & Jozefowicz, 2008; McBeath & Webb, 2002; Ungar, 2002). The use of this theory as a framework for the development of theories in specific practice settings makes it amenable to the task at hand: understanding the experiences of individuals and families in their journey from diagnosis to the end of life. This journey has been explored through the use of an ethnographic methodology which will be described in Chapter Four.

Chapter Four

Methodology

‘What does an ethnographer do?’ Geertz . . . asks; and the answer is, here as elsewhere, ‘He writes’. (Richardson, 2003, p. 87)

4.1 Introduction

This chapter outlines the rationale for selecting a qualitative methodology, and the issues that arose in the research process. The research methodology employed to collect data was ethnography; therefore, a discussion of the application of this methodology is provided. My previous professional and personal experiences that informed my choice of methodology and topic are briefly discussed. Issues encountered on entering the field, participant recruitment, engagement, and leaving the field are outlined. I then explore the data analysis where I draw on narrative and grounded theory methods and describe how I used a computer analysis programme to assist with the management of this analysis. Some of the methodological and ethical issues arising from the research as well as the strengths and weaknesses of the methodology are considered in closing.

4.2 Method Selection

Qualitative research lends itself to the in-depth study of a small group of people from which “rich, textured data” (Herman & Reynolds, 1994) can be collected. It celebrates diversity, as opposed to looking for common patterns that can be used to make generalisations (Davidson & Tolich, 2003). It is an inductive (as opposed to deductive) method that draws on context and interpretation in understanding people’s experiences. It

also places value on the personal involvement and subjectivity of the researcher and, therefore, provides an empathic fit with reflective processes used in social work research and practice (Connolly, 2001). It is a highly flexible approach that is data driven, enabling the researcher to follow up on ideas or issues as they arise.

Qualitative research methods allow data to be collected in a variety of ways, such as through participant observation, semi- or un-structured interviews, and document analysis. Therefore, it is particularly helpful when researching a group of people for whom language may be difficult. For this reason, as well as for the reasons previously listed, a qualitative approach involving participant observation and document analysis techniques, can be regarded as suitable for research in the health field where patients may be too unwell at times, or unable for other reasons, to verbalise their thoughts and feelings.

4.2.1 Ethnography

Ethnographic research methods are not uncommon in social work or in palliative care, and many authors have discussed the perceived value of ethnographic research (Alston & Bowles, 1998; Clark, 2000; Fortune, 1994; Padgett, 1998; Sissons, 2003). Ethnographic research designs are most appropriate when the research project clearly signifies the intention of taking culture into account. Ethnography draws significantly on the ability of an individual to learn a new culture by being part of it (Maso, 2001). Hammersley and Atkinson (1995) suggest that:

In its most characteristic form ethnography involves the ethnographer participating . . . in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions—in

fact, collecting whatever data are available to throw light on the issues that are the focus of the research. (p. 1)

When encountering a new cultural setting, the ethnographer needs to be aware of behaviours or beliefs that the members of the culture may have internalised in the process of being socialised into that culture. Internalised behaviours may be perceived by the members of a cultural group to be the automatic responses to given situations, even though they have actually been learnt. That is because these behaviours have become habitual and are carried out with little conscious forethought (Maso, 2001). Culture is, therefore, learned behaviours, learned processes of socialisation that allow one to become part of the particular culture. Very rarely is one person's culture identical to another person's within the same society; therefore, ethnographic research is able to be used within, as well as across, different cultural groups. Even if the ethnographer has had similar experiences to the subjects, ethnographic methods may be used to help make implicit meanings explicit, and to investigate shared assumptions about behaviour and beliefs (Maso, 2001).

Using an ethnographic methodology allows the researcher to observe relationships, the means by which humans develop an understanding of their place in the world (Hawthorne & Yurkovich, 2003). The contribution made by Schultz (1964) is discussed by Holstein and Gubrium, (1994, p. 263) who explain that the way in which "ordinary members of society constitute and reconstitute the world of everyday life" depends on the "stock of knowledge" they have. The term "stock of knowledge", introduced by Schultz in 1964, is used to refer to the resources and knowledge that people have on entering the social world and engaging with it. The knowledge and resources are based on the individual's values,

norms, morals, attitudes, and ideologies. Drawing on this stock of knowledge assists the individual in making meaning from their involvement in, and engagement with, the social world (Holstein & Gubrium, 1994).

4.2.2 Participant observation and ethnography

Participant observation and ethnography can be utilised to provide an interpretive and humanistic approach to research. The same methods can also be used, however, to apply a more objective scientific logic. Given that my background is in social work, I was keen to explore the use of a methodology that built on the basic tenets of the social work philosophy. This required developing a working relationship from which to explore the participants' worlds and experiences as they related to my subject area: palliative care. In my role as researcher, I was able to observe participants in relation to other family members, members of the public, and health care professionals. Additionally, I became an observer who participated.

O'Reilly (2005, Foreword) describes the use of an ethnographic methodology very simply as "a methodology that acknowledges the complexity of human experience and the need to research it by close and sustained observation of human behaviour". She describes the purpose of participant observation as engaging in people's lives in a natural manner in the hope that the researcher's presence will cause little disruption, and that, in time, the participants will forget the researcher is there and act in a natural manner. This role is described as semi-overt, in that the participants know what the researcher is doing, but over time, they become less conscious of the researcher's role. O'Reilly suggests that it may be

helpful to predetermine the roles we may fill in the course of our ethnographic research. Whilst we are clear that our overt role is to collect data, in ethnographic research there are many other roles we will fill in the course of the research. She suggests that it is helpful to have some clarity about the roles we can fill so that participants can better understand our presence and participation in their lives (O'Reilly, 2005).

What I discovered was that in each of the research relationships with participants there were significant differences in the type of contact that was established and maintained, as well as varying levels of observation and participation. The factors that influenced the nature of the research relationships were: the availability and presence of other family members in a supportive or non-supportive role; the physical place in which the research was taking place; the time constraints of the participants and the researcher; the severity of the participants' illness; and the nature of the research/participant relationship, the goodness of fit. The roles I filled in the participants' lives often indicated gaps in the support services that were available; these are discussed more fully within the findings chapters, Chapters Five to Eight.

4.2.3 Positioning the self in ethnography

Increasingly in qualitative research, discussion about the social research relationship is focused on the experiences and emotions of the researcher. This is in contrast to conventional methods wherein the researcher maintains a neutral stance and emotional distance. In Coffey's (2002) article on ethnography and the self, she argues that "the researcher self has become a source of reflection and re-examination; to be written about,

challenged and in some instances celebrated” (p. 313). Coffey expands on this by referring to “the position adopted by Charmaz and Mitchell” (1997), which she suggests “occupies a middle ground here”:

They argue that just as there is merit in humility and deference to the views of Others, and to reasoned, systemic discourse, so too is there merit in ‘a visible authorship’. While the words of the ethnographers are neither magical nor authoritative, neither is the author’s voice a biased irrelevancy. They advocate vocal texts where the author is an active and visible participant. (p. 324)

Adding the personal narrative to the fieldwork journal and the fieldwork notes has long been held as acceptable practice for recording the researcher’s emotions, feelings, and process as the fieldwork progresses and the research relationship deepens (Coffey, 2002).

Approximately one month into the fieldwork process, both my supervisors suggested that I make a three-column template for typing up transcripts of jotted field-notes. I had been using a page split into two columns at this stage. In one column, I was recording all the details of the fieldwork. In the other, I was engaging in preliminary analysis of the data, as this is an emergent process that occurs alongside data collection in grounded theory (discussed in more detail in 4.6.1 below). My supervisors encouraged me to write my own process down as I travelled the road of palliative care with my research participants.

In the first column of the new template, I recorded the details of the research event. This included the full context in which the observation was taking place, which participants were present, other people involved in interaction with the research participants, and as the researcher, my interactions with the participants. The second column, the first analysis

column, was where I began the initial coding and this continued throughout the research process. The third column allowed space for me to record my emotions, personal thoughts, and my ongoing reflective process. The understandings gained or the questions that arose in this process were then integrated back into the fieldwork and the research analysis. This process became a valuable tool for developing reflective fieldwork practice, for resolving difficult experiences in the field, and for highlighting further areas of enquiry as expected when utilising grounded theory data analysis.

Due to the nature of ethnographic fieldwork, it is often difficult to write full notes in the field. Using the method of recording jotted field-notes and then typing up full transcripts at the end of the observation period required that I memorise a lot of information. At the end of each fieldwork session, I engaged in writing up the full field-notes which became my primary process for debriefing and resolving what were, at times, deeply upsetting and disturbing experiences. This process became an invaluable tool, which assisted me in dealing with the grief associated with the many deaths that I experienced during the fieldwork component of the research, as well as the losses encountered along the way. Furthermore, this process informed the ongoing practical fieldwork and analysis. As I gained more knowledge and understanding of the journeys the participants were on, my understanding of their experiences deepened. As I gained deeper insight into their experiences, I was able to consider theoretical explanations or views that provided a “different” way of understanding. Standing back from the participants’ experiences in this way allowed me to understand the parallel process that was occurring throughout the

fieldwork. As I explored the participants' immersion into hospital culture (see Chapters Six and Seven), I became aware of my own immersion in the lives of the participants.

Writing of the "self" in ethnography is common and takes many forms ranging from personal disclosure of the researcher's experiences in the field to a form of autoethnography (Ellis & Bochner, 2000), such as produced by Okely (1999). The ethnographer can become a central figure in the text, or their experiences may be recorded as a parallel process alongside that of their participants. Coffey's (2002) text explores the boundaries between autobiography and ethnography. She explores the emerging move of contemporary ethnography towards inclusion of the researcher's experiences and contrasts this with conventional ethnography in which the ethnographer is largely silent. Coffey argues that the current period in qualitative research merges the personal and ethnographic self and is part of a strategy to put the researcher/self back into the qualitative text.

To what extent the self becomes a part of the final analysis has been debated since the practice of personal narratives began in the mid-1970s. It is, however, seen as appropriate and desirable to separate these personal accounts from the data proper, and to use personal disclosure in moderation (Coffey, 2002). There are exceptions to this guideline, and some contemporary ethnographies, such as Okely's (1999), provide an autobiographical account in which the self is located firmly in the text. Coffey (2002) suggests that although autobiographical accounts of illness and the body can be seen as blurring the boundaries between ethnography and autobiography, they do, in fact, create a symbiotic relationship from which autoethnography has developed.

4.2.4 Researcher's experiences contributing to method selection

Previous participation in the field provided me with a rich resource with which to begin the proposed research. This base of knowledge and understanding was then enhanced and expanded through the process of reflexivity combined with the ethnographic research methodology. It was important, therefore, that the knowledge that I had gained from my own experiences with death and dying be allowed to inform the research process. These experiences were briefly discussed in the introduction, Chapter One.

Kohn and McKechnie (1999a) argue that the “contextual experiences” of people who are in the position of caring for someone who is dying can add a degree of knowledge to the research. Okely (1999) takes this argument a step further by suggesting that research methods, such as ethnography, which attempt to provide an “insider’s” perspective, may sometimes fail to do so as the researcher can still be located outside the individuals’ (people being studied) experiences. As an example of the researcher/personal-carer experience, Okely (1999) draws on her own experiences of caring for her mother until her death. In her article “Love, Care and Diagnosis”, she explains the importance of bringing our own experiences into our discussions. She also discusses the “flawed nature of experts’ knowledge” (p. 20), when they deny knowledge gained from lived experience and the wealth of information that can be gained from listening to “grounded indigenous knowledge based on practice [and personal experience] . . . and ethnographic knowledge grounded in participant observation” (Okely, 1999, pp. 21-22).

4.3 Ethics Approval

Ethics approval was sought prior to the research being undertaken. Taking the nature of the research, and the research settings, into account, ethics approval needed to be gained from three different ethics committees. Ethics approval was firstly sought from the Canterbury District Health Board's committee, the "Canterbury Ethics Committee", as this was required for conducting health research with human subjects. Concurrently, it also needed to be obtained from the Nurse Maude Ethics Committee, as the Nurse Maude Palliative Care Team was assisting with participant recruitment. The decision to obtain ethics approval in this order was because the approval of these two committees was required before the research could continue. Finally, ethics approval was obtained from the University of Canterbury Human Ethics Committee, as I am a University of Canterbury student.

There are specific ethical issues that arise when conducting research in the palliative care area. Perhaps the major concern is that participants are a very vulnerable group, as they may be experiencing a significant amount of pain and discomfort (Randell & Downie, 1996). Therefore, gaining informed consent from participants via the appropriate channels (through members of the Nurse Maude Palliative Care Team) had to be done in a manner that did not exert pressure on the participants. This was achieved by having people other than the researcher provide information about the research and, therefore, allowing participants to decide whether they wanted to be involved. Secondly, as time was limited for these participants, it was important to consider whether they should be free to spend this time with their family and friends, rather than take part in the research. The recruitment

approach that was approved by the three ethics committees ensured that participants who did volunteer did so without any duress. In that way, terminally-ill people who wanted to be involved were able to indicate this to the palliative care team. I then contacted the prospective participants and offered them the opportunity to contribute to the study.

4.4 Research Participants

Initially, access to participants was arranged in negotiation with the community palliative care team. Participants were people with incurable cancer and members of their families (or significant others) who were receiving the services of this team. The aim of the study was to engage in participant observation and to conduct semi-structured interviews with a total of ten individuals who had a terminal illness, and their families, over the period of a year's fieldwork. There was no minimum time requirement that participants needed to be involved in the study for data to be collected and used in the analysis. Following ethical approval, in consultation with the community palliative care service, initially 50 information packs were handed out to potential participants (see Appendices A-D). This written information provided an overview of the research and invited people who were interested to take part in the study. The information packs were given out by the palliative care team Clinical Nurse Specialists (CNS) on their first home visit to a person with a terminal illness. People who indicated that they were interested in taking part told the next visiting nurse specialist; the nurse specialist passed this information on to the hospice secretary, who then made contact with me. I then made contact with the potential participant and arranged to visit people who were willing to be involved in the research. During the visit, I fully explained the research to them. If they agreed to be involved, I asked them to sign the consent form.

4.4.1 Recruiting participants

By the end of a year of intensive fieldwork, the community palliative care team had referred six families to me. I found maintaining meaningful contact with six families to be time consuming and realised that participant recruitment would probably need to occur in two phases to successfully manage a maximum goal of ten families. This approach is fairly common in ethnographic research. As Atkinson and Hammersley (1994) explain, ethnography allows the exploration of particular social phenomenon, as opposed to testing set hypotheses. It involves the exploration of a small number of cases, or a single case in detail. In another ethnographic research project exploring collusion in doctor-patient communication which led to false optimism about recovery, the researchers note that it is not possible to maintain in-depth contact with any more than 15 patients and their families (The et al., 2001).

The original stated intention in this study, as noted above, was to have approximately ten participant families involved in the research. What I discovered in working with the community palliative care team in the recruitment process was that people were often referred at a very late stage in the disease process, and were often too unwell to become involved in research. The nurse specialist had been successful in selecting six potential participants who were expected to live for at least a few more months; however, these participants, who were referred to the service fairly early on in their disease process, were the exception to the rule. As I still required more participants, I had to decide whether to extend the fieldwork for a further six months. I wanted to gain access to potential participants who were not in late-stage cancer, as those who were being referred to the

service often were. I had discovered in my contact with the first six participants that the majority of them were still receiving treatment through the public hospital oncology department, even though they had been referred to the community palliative care team. Therefore, in consultation with my supervisors, I made a decision to extend the fieldwork component of the PhD, and recruit another four families through the oncology department. I approached the oncology department and requested permission to recruit four participant families through their service. After receiving preliminary permission from the head of oncology to do so, a formal request was made to department of oncology. My request was granted and a decision was made to recruit the new participants through the hospital palliative care team. This variation in the recruitment process also involved gaining ethical consent for an alteration to the original ethics approval. Formal approaches were made to The University of Canterbury Human Ethics Committee and the Canterbury Ethics Committee for permission to extend the period covered by ethics approval as well as permission to alter the recruitment process. Permission was received from both committees. A total of 10 research packs were made and delivered to the oncology department for distribution by the palliative care team.

I followed up on three referrals from the team. The first of these referrals was to a woman who was in the oncology ward at the public hospital. I was asked to wait two days before seeing her, as she was being transferred to the hospice. When I arrived at the hospice two days later, I was told the woman was now dying. I spoke to a family member and expressed my thanks for her mother's willingness to be involved in the research, and my understanding that she was probably too unwell to be involved. The family member

explained that her mother was no longer able to speak, and confirmed that it was probably too late. I wished them all the best.

The second referral was to a man who was currently at home. I was given his home phone number and I called and spoke to his wife. She explained that her husband was now quite close to death and he was quite confused about the number of people coming and going from their home. She thanked me for my call but felt it was too late for their involvement in the research.

The third referral was to a woman with late-stage cancer. Although I met with her a number of times and have some field-notes, I was unable to use this data or to include her as a participant as she did not sign the consent form, although she had wanted to sign the consent form at the same time as her husband. I made several attempts to establish contact with her husband but was unsuccessful. Her health rapidly deteriorated, and she and her husband, as a couple, were quite overwhelmed. After my discussion with her, I felt it was only ethical to thank her for her willingness to participate and to withdraw.

Through engaging in this process, I learnt that the majority of referrals to the hospital palliative care service also tended to occur quite late in the disease process. The community palliative care team had explained that people were often unsuitable for the research because they were very ill by the time they were referred. As previously explained, I had hoped to combat this problem by applying to recruit participants through the oncology department. Instead, I discovered a corresponding pattern of late referral; people are only

referred to the hospital palliative care team in the final days of life. I had to consider other options of gaining access to a few more research participants. Eventually, I was able to recruit two more research participants who volunteered to take part.

4.4.2 Volunteer participants

The next two participants both volunteered to be involved in the research project. Contact with these two participants was through a third party who was aware of my research and made contact with me. The idea of using participants who had volunteered was discussed with my supervisors. They felt that it would still be within ethical guidelines to accept volunteers as long as they met the research criteria. These criteria are outlined in the ethics application and state:

It is intended that participants will be English speaking as understanding what participants are talking about is required by this particular research methodology. The participants with a terminal illness will be over 18 years of age, as younger patients are not usually referred to [the community palliative care team] (agency involved in recruitment of participants). Because recruitment of participants is being carried out in negotiation with the community palliative care service, it is also a requirement that participants have been referred to this service. Participants will only be included if they have provided written informed consent. (Ethics Application, Form EA 05/02, p. 5)

The potential participants were introduced to me by people I knew personally. After establishing that they met the criteria for participation, including that they were involved with palliative care services, they signed consent forms and became my seventh and eighth participants.

4.5 Leaving the Field

In November 2006, I made a decision to end attempts to recruit further participants as time was becoming a major issue, and recruitment of further participants was becoming impractical at this point. By this stage, I had spent a total of 20 months in the field and had collected data from over 300 field visits to participants. The data had been converted into typed field-notes which were ready for the more formal process of analysis. Data from the ongoing contact with families and with participants seven and eight were continually added into the analysis as soon as the field-notes were transcribed.

In total there were eight terminally-ill participants and 83 family members involved in the research, a total of 91 participants. All of the eight ill participants died during the research process. The last participant died in September 2008, which was three-and-a-half years after I began the fieldwork. I maintained contact with family members of the deceased participants during the data analysis and writing-up process, and post bereavement. This ongoing contact relates to my position as a participant observer, ethnographer, not my professional role as a social worker. The very nature of ethnography requires that the researcher establish rapport and develop “friendly working relationships based on personal contact” which involves taking part in peoples’ lives as we study them (Kottack, 2002). The personal nature of this research methodology, and the fact that the field of enquiry concerns the journey towards death, contributes to a situation where immediate disengagement from bereaved family members is inappropriate. Family members wanted to maintain contact, as doing so provided an opportunity to talk about their loved one who had died. They often found it difficult to have these discussions with other family members

who were grieving. This ongoing contact also assisted me in the process of clarifying information from the field-notes, and provided me with opportunities to reflect on my involvement in the lives of the participants, many of whose deaths I was also grieving. Individuals within families asked me for copies of my field-notes following the death of their family member. This raised ethical issues about confidentiality and ownership of the data. In discussion with my supervisors, I clarified these issues and made a decision to send a covering letter (Appendix E) along with a reflective letter (Appendix F) to family members who requested information. This letter was included with transcribed field-notes (Appendix G) that involved the individual family member making the request.

Due to my ongoing contact with family members, some of them became aware of my diagnosis with cancer in 2008. One of the participants, Billy, was still alive when I was diagnosed, and his sister, his parents, and his friends provided me with practical and spiritual support. Contact with other family members included Bill, Joan's partner, who was also diagnosed with cancer around the same time and we became great allies for each other on our journeys. Helen's husband Chris stayed in monthly contact with me after Helen's death, and he also offered much support after my diagnosis. The remaining family members maintained contact via texts or emails for approximately six months to a year after the death of their loved one.

4.6 Data Collection

An ethnographic research design was used to collect data from observations, informal interviews, and semi-structured interviews over the period of the fieldwork. Drawing upon

the concepts developed by Geertz (1973) and Spradely (1979), Clark (2000, p. 2) states: “With its focus on accessing ‘lived experience,’ an interpretive/ethnographic perspective offers a different ‘way of knowing’ that is inductive, reflexive, dialogical, meaning-focused and contextualised.” This qualitative research paradigm provides a situational and systematic perspective that allows the researcher to observe lived experience and the meanings attributed to those experiences (Clark, 2000). Rock (2001, p. 30) states: “Ethnography . . . alludes to the situated, empirical description of people. . . .” Ethnography is also known as “participant observation” or “fieldwork”, according to Davidson and Tolich (1999), where the researcher goes out into the “field” and collects data in a natural setting. Sissons (2003) describes the essence of ethnography as consisting of observation, interviewing, and participation. Bailey (1996) argues that the purpose of fieldwork is to understand the daily lives of the people being studied, by engaging in a prolonged observation of everyday life. She explains that the nature of fieldwork is that it is carried out in the “field” of interest, and it is a type of data collection process that is not controlled by the researcher. An example of this from my own research would be the observation of a research participant and health care worker in the hospital setting. The researcher becomes involved in the lives of the participants, thereby, experiencing the daily lives of the participants in order to accurately describe the meaning of events.

There were two means of logging the data: written field-notes from participant observation and informal interviews, and transcripts of semi-structured interviews. Writing field-notes is the process whereby the researcher turns their experiences during participant observation into written notes, and is one of the primary methods of recording participant observation

in ethnographic studies (Emmerson, Fretz, & Shaw, 2001). Field-notes are a descriptive form of selective representation of the researcher's observations and reflections, not an exhaustive account of events. The process of making mental notes, jotted notes, and then writing full field-notes at the end of the day, as suggested by Lofland and Lofland (1995), was used in the study. A guide was also developed for the purpose of conducting semi-structured interviews. The semi-structured interviews were audio-taped when appropriate, and transcribed. Planning of interviews depended on the participants' ability to participate, and priority was placed on the well-being and care of the participants over the collection of data. Participants were told that they could withdraw from the research at any time and that this would not compromise their access to, or the standard of, their health care. They were also told that confidentiality would be maintained whether they continued as participants or not.

4.7 Data Analysis

For the purpose of writing this methodology chapter, I have, for the most part, separated discussion of data collection from data analysis. It is important to note, however, that in ethnographic research the collection of data and the analysis of data are intrinsically linked. O'Reilly (2005, p. 177) refers to ethnographic research as drawing on an "iterative inductive approach" and suggests that instead of seeing data collection and analysis as a linear process we need to see it as a spiralling process. I found this to be a more apt description of the research process. Writing up my field-notes often made me aware of issues that required further exploration; this further exploration would then result in further field-notes being developed and so on. Although there was overlap of data collection, data

analysis, and writing up, there were also phases where I was engaged in one activity more than others. Over time, certain themes began to emerge that I recorded so they could be included in the more formal data analysis process. Just as data analysis occurred during the fieldwork phase, fieldwork continued during the data analysis phase. This process is summarised by O'Reilly (2005, p. 177): "The phases of writing down, analysis and writing up are distinct phases of the research process that are inextricably interlinked".

In an ethnographic study by The et al. (2001), data were collected from observations of patients' interactions with health care workers in different hospital settings and during home visits, as well as from informal conversations and more formal interviews. A similar approach was used in my research process. A massive amount of text was hand written in the field, and this was converted into typed documents in order to use the computer software programme, NVivo 7, for analysis. Denzin (1994) refers to the collated field-notes as the research text. This text contains initial interpretations of the field-notes but needs to undergo another process of interpretation to draw out meanings and to begin to make sense of the fieldwork experience. He refers to this text as "a working interpretive document" (p. 501). From this text, the researcher creates a "quasi-public text" that can be shared with others involved in the research process. From here, the document is changed into a public document, such as a thesis or research article.

In the interpretive process of writing, the researcher needs to determine how they wish to situate themselves in the text. Denzin (1994) explains that the researcher presents a unique, situated self in the text in a manner that clarifies the researcher's authority and credibility

about the research material. According to Denzin, “Four major paradigms (positivist and post-positivist, constructivist, critical) and three major perspectives (feminist, ethnic models, cultural studies) now structure qualitative writing” (p. 502). The perspectives and paradigms chosen serve several purposes. Firstly, they proffer a mask behind which the researcher presents their unique self in the text. Secondly, they prescribe a world order which structures the writing process. For example, a constructivist approach would highlight emerging patterns and understandings (Denzin, 1994). Excepting the positivist position, the major qualitative perspectives identified by Denzin (1994) influenced and challenged the approaches used in this research project at various junctures.

Once the researcher has clarified their approach to writing they need to move from the field-notes to the text, and this can raise other issues. These include sense making, representation, legitimation, and desire (Denzin, 1994). Sense making includes making use of memos and code notes, as outlined by Strauss and Corbin (1990). Representation raises the issues of “voice” of “self presentation”. Denzin (1994) argues that it is only by presenting a “multivoiced text” that the ethnographer allows voices of “others” to be heard alongside their own. Legitimation raises issues of reliability, validity, and generalisability in presenting a legitimate, authoritative text. Desire is about creating a vital text that places the author in the text and invites the reader to become involved in the journey or story. Finding meaning in the field-notes and enabling this to emerge through the process of interpretation and then finding an appropriate manner for representing this meaning is what the writing process is all about (Denzin, 1994). I managed this process throughout data

collection by recording notes in a three-column template, as discussed in 4.2.3. The third column contained my own reflective process; the ethnographer's voice.

Proponents of ethnographic research suggest that it is unwise to determine at the outset exactly what form of analysis will be used to explain the data being collected. Lofland and Lofland (1995) state:

In qualitative fieldstudies analysis is conceived as an *emergent* product of a process of gradual induction. Guided by the data being gathered . . . and the topics, questions, and evaluative criteria that provide focus, . . . analysis is the fieldworkers' *derivative ordering* of the data. (p. 181)

Certain forms of analysis suit ethnographic studies. Two of the suitable forms of analysis utilised in this research are grounded theory and narrative analysis (Lofland & Lofland 1995). Narrative analysis is a tool that can be used to complement other forms of analysis in an ethnographic study. It is not sufficient on its own, however (Cortazzi, 2001), but may be used along with other forms of analysis, such as grounded theory.

4.7.1 Grounded theory

Grounded theory, originally developed by Glaser and Strauss (1967), is a useful methodology by which to manage an inductive analysis in which questions, answers, and propositions emerge from the data and are interpreted by the researcher. In keeping with the research methodology, during the sorting and categorising of data (coding and memoing), attention is paid to the data collected from the subjects, the context in which the research took place, and the researcher's process as the central agent in the emergent induction (Lofland & Lofland, 1995). It was my original intention to review and code the data as part

of the collection process, to identify emerging themes and follow up on them, to highlight the productive aspects of the data collection process, and to identify areas where more data may be required (Davidson & Tolich, 2003). Systematically reviewing the data during the collection process is one of the main tenets of grounded theory (Merriam, 2002). I found, through this review or reflective process, that I was able to identify emergent themes that became “nodes” in the more formal process of data analysis. As Atkinson and Hammersley (1994) note, coding of data during the collection process is not according to set analytical categories. Data analysis involves working with a substantial amount of unstructured data which tends to be explored in terms of the meanings and understandings that underpin the human experiences under investigation. Analysis often takes the shape of in-depth description and explanations and draws on statistical analysis in a limited capacity, if at all (Atkinson & Hammersley, 1994).

Pidgeon and Henwood (2004) outline the essential analytic strategies that are used for the generation of theory from data in a way that usefully reflects the approach taken in this study:

1. developing open-coding schemes to capture the detail, variation and complexity of observations and other material obtained;
2. sampling data and cases on theoretical grounds, and as analysis progresses, to extend the emergent theory (‘theoretical sampling’);
3. constantly comparing data instances, cases and categories for conceptual similarities and differences (the method of ‘constant comparison’);
4. writing theoretical memoranda to explore emerging concepts and links to existing theory;
5. continuing to make comparisons and use of theoretical sampling until no new or further relevant insights are being reached (‘saturation’);
6. engaging in more focused coding of selected core categories;

7. tactics to force analysis from descriptive to more theoretical levels (such as writing definitions of core categories and building conceptual models). (p. 629)

I have also drawn on narrative analysis, particularly in Chapter Five, which contains the research participants' retrospective stories leading up to and including diagnosis. I felt it was more fitting to employ narrative analysis in this chapter as the research participants naturally engaged in narrative discourse to tell me their stories of diagnosis.

4.7.2 Grounded theory and the NVivo programme

As previously discussed, ethnographic research designs provide thick, descriptive data. Grounded theory analysis can usefully be employed with this data, as ethnography is a natural method of enquiry and grounded theory works most effectively on data generated in natural settings (Pettigrew, 2000). Working with the sheer bulk of data collected from approximately three-and-a-half years in the field, led to the exploration, and eventual use, of the computer software programme, NVivo 7. This software was used for data entry and organisation, as it is a theory-building software that is ideal for research that is qualitative. The researcher can search and code the text and use the NVivo 7 software programme to create classification codes relating to the meanings drawn from the data. In terms of grounded theory methodology used in this study, the software assisted the identification of conceptual categories from constant comparison of the classification codes. From these conceptual categories the underlying themes were identified. These themes were then explored using complex data searches, for example, by intersecting coded information and collecting the resultant information under nodes on a tree structure. This process highlighted the similarities and differences across each theme which, on further exploration

and comparison, led to the development of the two core categories of “time and place” and “preparedness for death”.

4.7.3 Narrative analysis

Narrative analysis is ideally suited to an ethnographic study of palliative care as it is a powerful tool for analysing significant transitions in people’s lives, such as terminal illness and death. “This can be a powerful research tool if the narratives are accounts of epiphanic moments, crises, or significant incidents in people’s lives” (Cortazzi, 2001, p. 384). However, narrative is not simply a recounting of what happened at a given point in time, it is imbued with the perspective of the teller (Cortazzi, 2001). A similar point is put forward by Alasuutari (1995) who discusses the use of life stories. He suggests that life stories can be regarded as retrospectively constructed documents that reflect the teller’s theories about life, as well as their construction of self. In a similar manner, Frank (1995) writes about illness as a “call for stories”, a way of making sense of the experience of illness. He explains that narrative methods attend to the co-construction of stories that reinforce the story-teller’s life and have a clear theoretical construction around them. In therapy, the narrative approach assists clients to deal with self-blame, make meaning of their loss and grief, create hope for the future, recall past experiences or people, and create a sense of social connectedness (Frank, 1995).

4.7.4 Research using narrative analysis

Alasuutari (1995) refers to stories as a “type of discourse with considerable cultural significance” (p. 71). He draws on the notion suggested by Prince in the early 1970s that

the simple structure of a story consists of three related events. The first and third events describe a particular state, such as well or sick, happy or unhappy. The second event is an active change in the person's particular state. Drawing on my own research, an example of this simple narrative structure would be: Jenny was always quite well, then she got cancer and began treatment, and now she was unwell a lot of the time. Alasuutari further argues that the analysis of narrative is not a difficult process; he draws on the notion of discourse analysis developed in the 1980s by van Dijk. Van Dijk devised a system of "reductive macrorules" which are then applied to the narrative in order to reduce it to a summary of the original story, a plot summary. These macrorules are: deletion/selection, strong deletion, generalisation, and construction. Alasuutari also refers to the founder of narratology, Vladimir Propp (1928, 1975), to explain that the reason for reducing narratives to plot summaries is that studying the structure of narrative provides a more accurate classification system than merely studying their content. More importantly, plot summaries allow the researcher to discover the uniting and dividing components of a multitude of narratives (Alasuutari, 1995). In my research, this tool became a useful way of comparing the lives of the participants involved, and of drawing out similarities or differences between the ill participants' stories.

A study carried out by Docherty and McColl (2003) investigated how people make sense of, and meaning from, their stories of illness. The study was phenomenological in nature and drew on social construction in considering the data. In their study, the social work researchers explored the stories of four participants who were living with chronic illness. Semi-structured interview data was analysed using grounded theory and then narrative

analysis. Riessman's (1994) approach to understanding personal narratives utilises coding to tease out the context and structure of the narrative and to understand how the narrative is embedded in social discourse. Her interpretive approach teases out the "ambiguities and paradoxes" in the text that indicate that there may have been many factors not discussed, or that the situation being narrated may be too complex to fully describe. In this regard, narratives are seen as partial, edited descriptions of an event. This does not mean that they are inaccurate representations of the "truth", they are what Riessman calls "narrative truth". Narrative truth is the presented version of reality given to the listener by the narrator, it is a story embedded in the experience of the teller at a particular point in time.

As an example, Tolstoy's story of the life and death of Ivan Ilych is examined by Freeman (1997) in an attempt to explore the notion of self-understanding and narrative integrity. He suggests that to understand the self, one must explore one's past and one's own history, "for it is precisely here, in the context of what I have already been, that I find the most suitable vehicle for coming to terms with whom I might be now" (p. 375). Freeman points out that the life story or narrative when reviewed may be creatively re-written by the person who is dying. They may look back and perceive their life through new lenses that shape their story in different ways from before. Freeman suggests that in these retrospective narratives of the life lived, there are often fictional versions of occurrences, shaped to the teller's wishes as opposed to accurate accounts of reality as it occurred.

Freeman (1997) goes further to suggest that some of the stories are in fact lies, invented to fulfil a particular purpose for the dying person. Freeman points out that if he looks back on

his own past, he can see it as wanting when he considers the knowledge he has now and what he now considers as other possible responses to situations he encountered. He explains that this process of life review leads to a sense of self-understanding that may have been previously lacking:

Self-understanding, as it occurs in the movement or rewriting the self, is always and inevitably an act of self-transcendence; it is an act of divesting oneself of a certain 'blind view' of things; of encountering face to face one's own otherness; and, ultimately, of moving on to a more fully-realised mode of being human. (p. 389).

Freeman refers to this process of striving for self-understanding as discovery of the embodied self. He says that part of the process of self-understanding is also to search for the greater meaning of life and death. Freeman suggests that when people live "unconsciously", this way of life is devoid of conscious thought about living, but it is also devoid of conscious thought about dying. Freeman suggests that when death becomes a conscious thought, whether through illness or some other life event, people appraise their lives to discover if their lives contain "narrative integrity", whether they are lives that have been well lived, whether they have a story that is worth telling.

During the course of my research, I was able to witness this intimate process of self-transcendence in varying levels of intensity. One research participant in particular, Billy, eventually gave up the life he had prior to diagnosis, and focused fully on preparedness for conscious dying. Self-gratification was a goal he actively let go off, as he used his limited energy and resources to develop a fully realised relationship with the omnipotent being in whom he placed his faith. Billy struggled all his adult life to achieve this goal, but it was

not until he truly faced the reality of his death that he was able to make the significant changes required to substantially alter his life path. Freeman (1997) suggests that the self-distancing that is required to achieve an accurate appraisal of life is often only achieved in older age or when someone is facing death. It is important to realise that there are many ways in which the process of self-understanding occurs and that these are embedded in time and place as well as the cultural milieu of the society in which the individual lives. Who someone is, what they remember, and how they tell their story, are socially constructed, and, therefore, different for each person. Listening carefully to the stories of others will assist in determining what was of value to them in the life they lived.

The very nature of ethnographic research means that researchers often uncover private information that could be embarrassing to either the person being studied, people within the field being studied, or the researcher themselves (Adler & Adler, 1993). Peacock (as cited in O'Reilly, 2005, p. 183) refers to ethnographic investigation as the shining of a "harsh light on a subject allowing us to see behind things, in corners and in shadows, and things we might have been missed if we were not open to surprises and things that try to stay hidden." It is not surprising then that this "harsh light" will reveal certain situations or issues that are very sensitive in nature. Therefore, the researcher needs to think very carefully about revealing sensitive information that may be contentious in nature. Adler and Adler (1993, p. 250) argue that "self-censorship, the practice of omitting selected facts and features of one's research findings, has been practiced by data gatherers for as long as the ethnographic tradition has existed." An additional issue that arises when using self-censorship, is the possible loss of narrative integrity. The authors also suggest that the

practice of “self-censorship” is one of the least talked about issues arising from field research.

4.8 Methodological and Ethical Issues

In the process of my fieldwork, I came across situations that were highly contentious, and which could be very embarrassing for the health care professionals or services concerned. I also came across situations that were personally distressing and disturbing, and was privy to information about the research participants that family members did not have access to. These contentious or disturbing issues often led to extra supervision sessions in order to debrief. I was still left, however, with the question of whether and how I disclose these situations in the writing up of this thesis.

One of the issues that arise with a small number of participants is maintaining the anonymity of the participants who are from a relatively small population group, that is, people with a terminal illness, namely cancer, who live in a particular city, and are involved with the same health care services. This relates to the issue of self-censorship discussed above. As Adler and Adler (1993) note, there are certain factors that prompt self-censorship. These include: the development of loyalties to the research participants; a sense of being beholden to the institution because of preceding negotiations that allowed the researcher access to people within the institutional setting; fear of creating stigma for the population being studied; the researcher’s personal or family matters; or the political climate. There is no doubt that self-censorship is a dilemma which raises ethical and moral issues that we need to acknowledge.

Adler and Adler (1993) also suggest that using disguise or masking may be a way of presenting the contentious information, whilst protecting the anonymity of the participants. Sieber (1992) states that one of the prerequisites for conducting ethical research into sensitive topics is to use a culturally sensitive research design, and to learn how to perceive sensitive issues from the participant's perspective, not just from the researcher's perspective. One way to determine if issues are as sensitive for the participant as the researcher thinks they might be, is to show a draft article to the participant and allow him or her to decide about the inclusion or exclusion of the information in the final writing up of the research. There could potentially be some pitfalls in this process, in that once seeing what is going to be written, the participant may decide that he or she does not want the work published (see Adler and Adler, 1993, for a discussion of situations where this has occurred). I have employed both suggestions in the writing up of this thesis. I have disguised contentious information that could lead to a loss of anonymity for the research participants, and I have given drafts of research findings to participants for input. I have also raised issues in a more general as opposed to a specific manner so as to remove details that may identify service providers or health care professionals.

4.8.1 Strengths and weaknesses

A wealth of rich data can be gathered in an ethnographic study of this nature and drawn on to understand the culturally constructed meanings of the process of death and dying for the people involved. Using an ethnographic approach to gather data is a less obtrusive way of collecting data at a highly sensitive and delicate time in the participants' lives. An ethnographic research design is also in keeping with the discipline of social work. An

ethnographic study can take the full cultural context of a person into account at one of the most sensitive points in someone's life, their journey towards imminent death.

Hammersley and Atkinson (1995, p. 264) highlight five ethical issues inherent in ethnographic research. These include: "informed consent, privacy, harm, exploitation, and the consequences for future research." The authors argue that it is difficult to gain informed consent from all the people who may become part of the "data" in ethnographic research. This problem arises because of the nature of the research methodology. For example, when I was spending time with my research participants in the chemotherapy suite or the oncology ward, I also observed health professionals at work. I observed other patients, other families or friends, and I wrote about some of the actions that I observed involving these people. I had gained informed consent from my research participants and family members, and I always asked health professionals for their permission to remain with my research participants. This often resulted in me providing a brief explanation of the research. An issue relating to this is discussed by Hammersley and Atkinson (1995) who state that an ethnographer often does not know exactly what they will write about in the final article as this often evolves as part of the research process. Hammersley and Atkinson also note that people who occupy the spaces that ethnographers spend time in may come to accept the researcher's presence and forget their explicit role. This is, of course, one of the goals of ethnographic research: to become a familiar presence in order to reduce reactivity or staged responses and actions (Hammersley & Atkinson, 1995).

Adkins (2002) argues that researchers need to ensure that the people they research do not become exploited as resources for their own self-formation. Inevitably, participants become resources, but this should be a by-product, not an aim, of the research. The risk of exploitation can, in part, be reduced by researchers acknowledging and being accountable for the use of resources, positions of power, and responsibility of the positions they hold. Acknowledging the reflexive self of the research participants makes the participant the centre of the story, as opposed to the researcher positioning themselves as the reflexive body and seducing the reader into believing in their authority and openness. Influence over the material is somewhat unavoidable, and whilst researchers may strive for a level of equality in the research relationship, they are unlikely to fully achieve this goal.

Patton (1990) argues that every qualitative research project that is undertaken is unique and, therefore, the data analysis process will also be unique. He explains that the nature of qualitative enquiry depends, in a large part, on the skills, background training, experience, and abilities of the researcher. Because of this, the process of analysis also depends on the “analytical intellect and style of the analyst”, which Patton refers to as the “human factor”. He argues that it is the “human factor” that is the main strength and also the most basic weakness of the qualitative process of data collection and analysis.

Earlier I mentioned that post-positivist and other critical perspectives influenced my methodology. Ecological, grounded, and other approaches are frequently noted to be vulnerable to positivist influences. Throughout my data collection and gathering I was conscious to ensure that these approaches were stretched, or “pushed around the post-

modern turn” by attention to consideration of time and place, insider/outsider perspectives, difference, reflexivity, self-understanding, and other aspects of context (Clarke, 2005).

4.9 Conclusion

Ethnographic research methods are most appropriate when the intention of the research is to take culture into account. Ethnography involves the participation of the ethnographer in the daily lives of the research participants. As the research relationship deepens, the researcher is able to explore each participant’s world, experiences, and the meaning of these experiences. Ethnographic research involves the researcher engaging in the participant’s world in a natural manner (O’Reilly, 2005) that meets the needs of both parties. As the research relationship develops, the researcher becomes a source of reflection and information. There is no attempt in this process to maintain a neutral stance or emotional distance (Coffey, 2002).

The three-column template I developed to record my field-notes assisted me in the process of reflection and further data collection, as is required in grounded theory. It also became a useful tool for debriefing at the end of a session or the end of the day. By using this tool, I was able to understand my own parallel process which occurred as I walked alongside participants on this journey.

Six families were recruited in the first year of the data collection phase, and the fieldwork component of the study was extended in order to recruit more participants the following year. The second recruitment phase highlighted issues around late referrals being made to

palliative care services, as many of the people who were referred were too ill to become involved. The final participants were both volunteers, one of whom died within a few weeks, while the other lived until September 2008. Contact with this remaining participant continued alongside the data analysis and writing up of the thesis. Field-notes were incorporated into the data as the thesis progressed. Narrative analysis was found to be most suitable for the retrospective data collected in my first meetings with participants. Their stories of diagnosis are presented in Chapter Five. The thick, descriptive data collected over the three-and-a-half years in the field were analysed using grounded theory with the assistance of the computer software programme, NVivo 7. Use of this software enhanced the building of theoretical concepts and core categories, as it enabled me to manage the bulk of field-notes and conduct complex data searches. The core categories of “time and place” and “preparedness for death” are presented in Chapters Six, Seven, and Eight, and discussed in further detail in Chapter Nine.

Chapter Five

Narrative Exploration of Diagnosis

By storifying a life we bring order to random happenings, make sense by reconstructing and reinterpreting. (Kohler Riessman, 1994, p.114)

5.1 Introduction

This chapter presents the stories of the eight participants who were diagnosed with incurable cancer and referred to the community palliative care team. The narratives fell into four groups: stories of protracted diagnosis; the existence of pre-existing medical conditions which complicated the diagnosis of cancer; stories of immediate diagnosis; and diagnosis of metastases. The focus of this research was to explore participants' experiences of palliative care. Participants were given information packs about the research at the time of their referral to the community palliative care team. Therefore, the data presented in this chapter, which explore participants' understandings of referral to palliative care, are retrospective in nature. This is an expected characteristic of narratives as making sense of an experience, such as being referred to palliative care, is a retrospective process (Czarniawska, 2004). The retrospective nature of this chapter is also due to the circumstances by which the participants were recruited, referral to a palliative care service.

This chapter draws on conceptual, interpretive narrativity (Lawler, 2003) to explore the first research aim: *to understand how individuals and families make meaning from the experience of being referred to palliative care services*. This aim developed in the early stages of my research design and was informed by reviewing literature relating to patients'

awareness of their diagnosis, their understanding of palliative care, and whether they were aware that the treatment they were receiving was palliative. All of the participants who had been referred to palliative care were under the care of both the public hospital oncology department and the community palliative care team.

The process of my engagement with participants began with my first home meeting with them, discussing the research, explaining the aims of the research, and gaining informed consent for their participation. In response to the information I had provided, participants began to tell their story of diagnosis and referral to the community palliative care team. In this chapter, I draw on a conceptual interpretive narrative style (Lawler, 2003) to illustrate the participants' sudden, dramatic, and life-changing experience of being diagnosed with incurable cancer. Narratives are more than simply stories that are fixed in time and place; they are an evolving construct that is imbued with meaning by the teller. The stories of diagnosis told by the participants are significant in that they highlight the pivotal moment when the participants' worlds and identities, and all they considered important, were irrevocably changed. Lawler (2003) states:

I see narratives as *social products* produced by people within the context of specific social, historical and cultural locations. They are related to the experience people have of their lives, but they are not transparent carriers of that experience. Rather, they are interpretive devices, through which people represent themselves, both to themselves and to others. Further, narratives do not originate with the individual: rather, they circulate culturally to provide a repertoire (though not an infinite one) from which people can produce their own stories. (p. 242)

In keeping with Lawler's description of narrative, the storied accounts of the participants' diagnosis can be seen as providing a context-laden explanation of how participants make

meaning of the experience of being referred to palliative care. In this chapter, I discuss how the participants understood their referral to the community palliative care team and how they developed meaning from this experience.

Lawler (2003) argues that narratives contain three basic elements: they must have characters, a plot line, and transformation, and these elements are bound together within an overarching plot. In Ricoeur's (1980) conceptualisation of narrative, he argues that plots are the central element of a narrative; they are not predetermined but develop through the process of emplotment. There are three processes to emplotment which make incongruent events into one cohesive story: beginning, movement, and end. In emplotment, one event leads predictably to the next event and so on to the end of the story, in this case diagnosis, which is understood as the finale of this stage of the story. Events that may seem unrelated are brought together to make a point, what Ricoeur (1991) refers to as synthesis which is culturally saturated with meaning for the teller, a point that will be perceived and understood as significant by the listener. Somers (1994) suggests that key events are selected from a repertoire of events that are used to create a narrative. She states, "The connectivity of parts is precisely why narrativity turns 'events' into episodes, whether the sequence of episodes is presented or experienced in anything resembling chronological order" (p. 616). The selection of events is based on their contribution to the plot, the point of the story.

5.2 Protracted Diagnoses

In the following two participants' narratives, the process of diagnosis was complicated and protracted as the participants' symptoms appeared similar to other medical conditions for which they were then treated. A third similar narrative was provided by Allan, who was a friend of Jack's, and was visiting Jack at home on the day Jack told me his story of diagnosis.

5.2.1 Jack and Allan's stories

I was visiting my first participant Jack, and we were sitting down with a cup of coffee and a slice of fruitcake when there was a knock at the door. Jack went to answer the door and came back into the room with a man he introduced as Allan, a friend who also had cancer. He then explained to Allan that I was there to learn about his experiences and suggested that Allan could help by joining in the conversation. I outlined the research to Allan and sought his consent to use the data collected that day in my research. Allan agreed and we all settled in the lounge to talk.

Drawing on Lawler's (2003) concept of narrative analysis to interpret the narrative text in my field-notes, we can see how two characters, Jack and Allan, tell their stories of diagnosis, to me the researcher. The plot begins with the two male characters discussing their current experiences with chemotherapy, and the care they were currently receiving, and then moves back through time to a discussion of the care they initially received from their general practitioners (GPs).

Jack says that he was unhappy all round with the way he was treated by his GP. He says, “He mishandled my case right from the beginning, and I can’t help but wonder if things might have turned out different if I had been diagnosed earlier.”

Allan says that if he had been given a simple chest x-ray by his GP, they would have known he had cancer, but the doctor never did a chest x-ray. He was told that he had a cold, “Hell of a cold,” he says.

The plot builds as the story moves onwards through successive GP visits and referrals to other health care professionals. Each event is synthesised into the totality of the story, and the process of emplotment culminates at the point of the story, the two characters’ diagnosis of cancer. The storyline then moves back to current time and the two characters’ awareness that social and cultural norms require that they be grateful for the treatment they are now receiving, and also that there is little point in blaming anyone as their fate can no longer be changed.

Jack says, “The hospital questioned why the doctor hadn’t done any of the right tests, but you can’t really blame anyone.”

Near the end of this narrative, the characters both state that they have found the oncology department very helpful. This comment may have been added because of my presence, (another character), and because I am writing field-notes as the story is told.

Through the process of telling the story, the teller’s identity is irrevocably transformed by his diagnosis. There are a lot of unspoken understandings. Both of the male characters have lived through similar experiences and are drawing on shared understandings of their journey. The point of the story, being diagnosed with cancer, does not have to be explained further by the characters because of the culturally-laden connotations and understandings of

the word “cancer”. The listener’s identity and role also has an impact on how the story is told. Both of the characters are aware of my role as a social work researcher, and given that my area of study is end-of-life care, there is also an unspoken understanding that I know what it means to be diagnosed with cancer. The story moves from present time to past time, and back to present time. There is a sense of frustration, lack of control, futility, and regret when the participants discuss the past.

The narrative leaves their unasked and unanswered question, “what if?” hanging: What if I had been diagnosed straight away, would I be dying now? Could something have been done then? Could I have had chemotherapy or radiation or surgery and been cured?

Jack and Allan’s combined narrative is their way of making meaning of the process of being referred to palliative care. The unspoken storyline, the meaning of the story, is: I have been referred to palliative care because my cancer wasn’t diagnosed in time, and now it is too late to be cured; now I am going to die. According to Lawler (2003):

Narrative, then, both connotes and constitutes movement—the movement from the potential to the actual, from what could be to what is, from past to present, from present to future. In the process, it works to *naturalize* the plot, making later events seem the natural and inevitable culmination of earlier ones Narrative provides a means of conceptualizing people in the context of history: if the past is always interpreted through the present, then equally this (interpreted) past informs the present. (pp. 250-251)

We can look at the narrative produced by Jack and Allan and see how their interpretation of what occurred prior to their diagnosis with cancer and referral to the community palliative care team evolves through the lens of current knowledge. Each of the episodes or events

they recount in the process of telling their story, is chosen because of their significance to the development of the plot. Jack and Allan may not have known at the time that each referral to a health professional and each visit to their GP was linked into one overarching story. The story that developed, the “social product” (Lawler, 2003, p. 242) is legitimised by drawing on cultural and social norms, what Somers and Gibson (1994) refer to as “public narratives” (as cited in Lawler, 2003, p. 251). Public narratives imbue the story with authority, they become truths because they are repeated often and are associated with expert disciplines and knowledge (Lawler, 2003).

Jack and Allan’s joint narrative creates a sense of conflicting values as the public narrative: “GPs are healers, the people who heal or help you when you are sick”, contrasts with the private narrative: “I saw my GP many times and I got sicker and sicker as the GP failed to heal me or to help me”. There is the underlying message that it may even be the GP’s fault that the participant was not diagnosed in a timely fashion and is, therefore, now dying. Lawler (2003) explains that the public narrative adds to the overall cohesion of the story, it saturates the story with meaning, it draws on cultural, social, and symbolic understandings of the world, and it aids interpretation of the narrative, as well as facilitating our understanding of the meaning and significance of the story. In this case, it also validates the story-teller, and it assigns cause or blame for the current situation to another person. It serves as an invitation to the listener, the researcher, to walk the rest of the journey to find out what comes next.

5.2.2 Joan's story

A very similar story was provided by another participant, Joan. It was my first visit to Joan's home, and I had just finished explaining the research to her. She asked me what the first thing was that I wanted to know. I told her that I would like to know about her referral to the community palliative care team. Joan and I were sitting at the dining room table, and Joan's partner Bill was busy in the kitchen.

Joan said, "Well I guess my story starts when I began to get sick, about three-and-a-half years ago, just after my husband Les died."

Joan then recounted the deterioration in her health and the ever-increasing fatigue she was experiencing. She also talked about the numerous visits to her GP and her growing concern and confusion about her ailing health. In a similar manner to the previous two narrators, Joan explained her frustration:

"It wasn't until 2004 that he acted and did something to help me. I had dropped to 36kg and couldn't stop vomiting." . . . Her doctor told her that she must have some sort of stomach virus and sent her home with anti-nausea medication. It didn't work and she kept vomiting, and he finally had her admitted to hospital. . . . "They put a tube down my throat and into my stomach and started draining something out." She said, "I told them that that it tasted like shit." She explained that the doctor said, "That's because that is exactly what is in your stomach."

The plot is very similar to Jack and Allan's narrative of seeking treatment from a GP and not getting the help they needed. As with Jack and Allan's stories, analysis of Joan's narrative also makes the implicit public narrative, that her GP would have the knowledge to help her deal with her illness, explicit. The GP can be regarded as the gatekeeper, the person through whom all referrals to specialists or access to specific tests need to be made.

If the gatekeeper does not allow this access in the initial visit, the person has no option but to return to the gatekeeper again and again, hoping they will change their mind and make the referral. Referral-based systems are intended to allay the costs of secondary health care, and to ensure that those who do access the system are the people who need it most. However, as noted in the New Zealand Health Technology Assessment (NZHTA) report (1998, p. 11), “Restriction of patient autonomy and access are inherent possible disadvantages of a referral-based gatekeeper system.” Along with issues of access to appropriate medical care, are the issues of deteriorating health leading to acute admissions. The NZHTA report indicates that the number of steps involved in an ill person being considered for admission could in fact be leading to the increase in the number of acute medical admissions. This situation is obvious in Joan’s narrative as the plot is one of worsening health and deterioration which links together various episodes of interaction in a meaningful way, to culminate in the diagnosis of cancer and the ensuing referral to the community palliative care team.

As a researcher seeking to understand Joan’s journey through palliative care, and her cultural identity, the narrative provides me with insight into her characterisation as a tenacious woman. The narrative helps to construct Joan’s identity: she is a widow, a hard worker, a mother, she is open to complementary healing, is resolute in finding answers to her problems, and can find positive factors to focus on (not having a stoma bag) while recounting a horrific experience. Joan’s identity is transformed during the telling of the story; she is no longer who she was at the beginning of the story. At the beginning of the story, she was a widow, running her husband’s business, active and always “on the go”. By

the end of the story, Joan is no longer active; she is now a woman with incurable cancer, receiving support from the community palliative care team. She is a woman who accepts the inevitability of her own death, and who is not afraid:

She explained that when they told her that her cancer was incurable and that she only had months to live, she told them she was okay with that, and they looked at her like she was mad. She said to me, "I'm not afraid, we all have to die at some point."

As the listener to this narrative, I was deeply affected by the extent of this character's suffering; I was drawn into the meaning of the story. The episodes recounted in the story affected me deeply as Joan was talking. Norrick (2000) would suggest that this is because Joan has been effective in targeting her narrative to her audience using teller strategies. Narratives must be tellable, if the audience is going to patiently listen to the episodic turns and twists as the story is emplotted (Sacks as cited in Norrick, 2000). The story must also be interesting in its own right and of interest to the audience (Norrick, 2000). In explaining my research to Joan, I had effectively communicated what I wanted to know about her experiences, and, in this particular visit, her experiences leading up to her referral to the community palliative care team. Therefore, Joan already had a captive audience and cues about which events to discuss, she had the telling rights and an appropriate story worth telling. In return, Joan provided cues as to how I might be expected to react to her story. She said, "*It got so bad*", she let me know that she was grieving the death of her husband, and she let me know that she was confused about her physical deterioration. She told me her story in a very matter-of-fact manner, allowing me to interpret the impact and meaning of each episode. As a social worker, my interpretation was influenced by my disciplinary background and professional beliefs (see Padgett, 1998). As a human being, my

interpretation was influenced by my own experiences of ill health, my mainly positive experiences with health professionals, my fear that this could ever happen to anyone else—or myself, and my belief that this was an enlightened era where access to state-of-the-art health care could be negotiated and would be provided.

In my field-notes, the day after my visit to Joan, I wrote the following:

This part of Joan's story really affected me, I almost felt sick thinking about it and it has haunted me all night. I can't get it out of my mind that she was allowed to get so sick and that her GP didn't see what was happening. What happened to her was revolting and no-one should have to suffer this type of indignity. I think about all the literature I have read about "dying with dignity" and wonder if it is simply a myth.

Although I was obviously upset and felt morally justified in judging the health professionals involved in the participant's story of diagnosis, I need to be aware, as Kleinman (2003) points out, that my feelings were not conclusive facts, but they were subject to further scrutiny, and they may alert me to certain issues that require further exploration. Smith and Kleinman (1989) analysed medical students' feelings of desire and disgust towards their patients, and found that "the ideal of 'detached concern' was tied to their authority; professionals . . . could be counted on as those who would 'set aside personal, emotional considerations in the interests of task accomplishment'" (p. 384).

Smith and Kleinman (1989) explored how the professional culture of medical settings silences talk about feelings. The researchers found, however, that there was an emotional cost. Medical students became desensitised to their patients and often dealt with feelings of discomfort by blaming patients and making inappropriate jokes about them. Kleinman

(2003) argues that it is vital that as researchers we include our feelings in our field-notes, as it is from exploring our own feelings that we begin to understand a variety of situations. Kleinman states that the inclusion of feelings and emotions in the process of analysis was legitimised by Hochschild in the 1980s, and in the practice of symbolic interactionism. Feelings can be seen as a resource, they can prompt us to question accepted understandings of how things are. “Only when we reflect on our initially puzzling irritability, revulsion, anger, or fear may we bring to consciousness our ‘gut level’ awareness that we are in a situation of coercion, cruelty, injustice or danger” (Jaggar as cited in Kleinman, 2003, p. 386).

As the participants reconstructed their narratives of protracted diagnosis, they were able to give voice to their grief and to the losses they had already encountered, but each of the narratives went beyond this point, if only marginally. There was a sense of hope and trust in their current doctors at the oncology department expressed in the stories of Jack, Allan, and Joan. This process is eloquently described by Kohler Riessman (1994, p. 114) in the quotation used at the beginning of this chapter: “By storifying a life we bring order to random happenings, make sense by reconstructing and reinterpreting.” The significance of each visit to the GP took on a new meaning in the process of storifying the unrelated events into a cohesive whole. Jack, Allan, and Joan all created a life in which hope was still present.

When I asked Joan if the doctors had given her any indication of how long she might live, she replied, “*No, not really, but we were told that I would be lucky to see Christmas and we*

saw that.” There was still hope that she would also surpass the current estimate that she may only have months to live. In their joint narrative, Jack and Allan had a conversation about how they believed the care they were receiving from the oncology department was good:

Allan says that the hospital is actually really good in many ways and Jack agrees with him. Allan elaborates by saying, “They are really onto it and know what they are doing.”

There is a sense of hope that they may receive the care they need after all, and there is also a sense of trust, which is all the more remarkable given the experiences they both had with their GP.

This sense of hope gave meaning to their stories of diagnosis. Diagnosis is not, therefore, perceived as a negative experience. For each of these three participants, it was the end of a struggle that brought access to better care and support. Diagnosis is, therefore, perceived as a positive experience. Diagnosis opened the door that the gatekeepers would not open; it gave them direct access to the oncology department and the community palliative care team. It gave the participants a sense that this was not an ending but a new beginning, a new journey, albeit a difficult one.

In a similar vein to the last two narratives I have presented here, Frank’s (2002) story of diagnosis with cancer in his book *At the Will of the Body* was one of worsening health and numerous visits to his GP prior to his diagnosis. He was finally sent to a sports medicine specialist who dealt with musculoskeletal problems, and this specialist felt his abdomen

and told him he had a mass in his abdomen. Frank asked the specialist what he thought it might be, and he was told that there was a possibility it was cancer. Frank explains, “By then I felt less terrorized by the idea of cancer than validated by a recognition that I was seriously ill” (p. 26). I imagine that after their prolonged illness the participants also felt validated by their diagnosis. After diagnosis came action and palliative treatment. Once someone knows what is wrong, they are then empowered to consider their choices and to make decisions. This is a position of power compared to the participants’ previous position of powerlessness, of disenfranchisement. This finding may, however, be context dependent. There are factors that may have contributed to the participants having a more positive outlook after diagnosis: they had never been diagnosed with cancer before, and they had all been to their GP many times and suffered deteriorating health before they were diagnosed.

5.3 Pre-existing Medical Conditions

In the following two narratives, the process of diagnosis was complicated due to pre-existing medical conditions. Neither of the participants had been diagnosed with cancer in the past, but they both had significant health issues that appeared to mask the existence of cancer.

5.3.1 Daniel’s story

Daniel was unable to talk for extended periods of time, so the story of his diagnosis occurred over a number of visits. Consequently, in his narrative there is a certain amount of repetition in the events discussed, and it does not flow as clearly and logically as the previous narratives.

I arrived for my first visit to Daniel and his wife Emily at their home. It was a very tidy, clean ownership flat, with a well-tended garden. After I arrived, we began by discussing general information, such as what Daniel did for a job, where he originated from, and where his wife Emily originated from. In response to my comment about wanting to know what it was like for them to be referred to the community palliative care team, they explained that they had a fantastic social worker at the hospital whom they called if they needed any help or assistance or did not understand information they were given. They were both positive about the oncology department and praised the doctors who worked there. Neither of them referred to the community palliative care team or what role, if any, this team played in their lives.

Daniel provided snapshots of his process of diagnosis over quite a few visits, with the result that the plot or the logic (Somers, 1994) of his story is more difficult to follow. It is still classed as a narrative account of his diagnosis because it contains the basic elements of a narrative, characters, plot line, and transformation. Each event that unfolds is linked into one cohesive story that develops in a linear process over a period of time (emplotment) (Lawler, 2003).

Daniel's narrative can be likened to a weekly television serial, where the story is revealed one episode at a time, as opposed to a movie-length story. Themes from one episode are either referred back to, or expanded upon, as the narrative is constructed. Episodes in Daniel's narrative of repetitive visits to health professionals prior to diagnosis establish a plot similar to Jack, Allan and Joan's narratives. His plot is dissimilar, however, in that he

was able to find a way around the gatekeeper by gaining direct access to specialists through the public hospital accident and emergency system. This is most likely due to the acute nature of his symptoms, he was having difficulty with breathing, and his past history of respiratory disease.

Daniel's first reaction to his diagnosis was to refuse treatment and retreat quietly to die ("go bush"). The reason he gave to support the logic of his thinking was based on his previous experiences with family members who died unpleasant deaths from cancer after receiving treatment. Whereas the participants in the previous two narratives felt a sense of hope about the immediate future after their diagnoses, Daniel's reaction was quite the opposite—that of hopelessness. This changed, however, after Daniel spoke to the oncologist about his options and the possible outcome of treatment. The oncologist was able to offer some hope to Daniel when he explained, "*It isn't the same for everyone*". When Daniel asked the oncologist if he recommended it, the oncologist apparently said it was "worth trying".

Del Vecchio Good, Munakata, Kobayashi, Mattingly, and Good (1994) conducted interviews with American oncologists to explore how they use their professional power to create narratives that provide a sense of hope for patients. They contrast the usual structure of a narrative, where a story builds through the process of emplotment by moving forward in time to a particular ending, with a different time structure that is focused on the present time only. The term "therapeutic narratives" is used to describe the doctors' discussions of treatment options with patients. Del Vecchio Good et al. (1994) discuss the inevitability of

endings when working with seriously-ill cancer patients, and suggest the discussion of endings is resisted by oncologists and patients when they are considering treatment options:

This resistance contributes to how oncologists seek to ‘emplot’ therapeutic action, how they attempt to formulate experiences for patients designed to instil hope and lead them to invest in often arduous and toxic treatments, how they structure time and horizons in attempts to avoid creating a sense of false hope or despair, and how they choose metaphors to engage patients in a struggle against disease and death, often largely shaped by the biotechnical context within which this occurs. (p. 856)

Del Vecchio Good et al. (1994) observed doctors’ avoidance of patients’ questions about prognosis and deference to the immediacy of current issues, such as clinical tests and “therapeutic housekeeping”, side effects of treatment, current medication, and other treatment options. In this research, Daniel’s narrative includes his decision, after a conversation with his oncologist, to give chemotherapy “a try”. He had his first session of chemotherapy and he said that he felt better after it. He did not experience any nausea or adverse side effects. In his narrative, Daniel moves from expressing a sense of hopelessness to being more positive and hopeful about the outcome of his treatment.

On my next visit to Daniel, he began talking about the family meeting held at the hospital to discuss his diagnosis. He referred to this event as significant in his story. Crossley (2000) suggests that significant events, which he calls “key events”, contribute to the cohesiveness of the story. Daniel related the events that transpired at this key event during two of my visits to him. Each account contains slightly different facts, but they remain congruent in nature. In the first account of the family meeting, the plot weaves around discussion of the

seriousness of Daniel's diagnosis and his thoughts about death and burial. Daniel told me how emotional this meeting was for him:

"There were a few tears and stuff and it was quite hard going."

The next day when I saw him, he provided more detail about the family meeting. Maybe he thought about it after I left, and wondered if I realised how significant this event was to him. This time he elaborated on how he felt during the family meeting and he also let me know that some of the tears he had referred to the day before were in fact his own:

He said that when he heard it being explained to his family, it really hit him and he started to cry.

This is the point in Daniel's narrative where his identity is transformed. He told me that he was aware of his own transformation:

He said, "This cancer has really changed me. I used to be really hard, now I'm softer. I want to just live every day I have now, not thinking about when I'll die, but just live each moment."

The meaning of the family meeting for Daniel is the focus of his narrative at this point. In his narrative he explains:

"I asked the doctor to explain what was wrong with me because I wanted my family to hear it from an expert, not from me, because they would pay more attention."

In other words, he wanted his family to understand the meaning of his diagnosis. He wanted them to hear it from the character in the story that has been attributed authority through his professional role (Kleinman, 2003), and through his role as the person who told

Daniel, the person who could now help, the person who later in the narrative offers hope. It may also be that Daniel did not feel able to manage the telling of his story, and that being able to hear his story, he would be assisted in processing the meanings it held for him.

As the new characters are introduced into the story, the focus moves to interpersonal relationships and concerns. Narrative serves to embed the characters within relationships, what Somers (1994) refers to as “narrative identity”. For example, when discussing the family meeting, Daniel told me about the importance of his relationship with his wife Emily and his belief that they will be together beyond death. He then told me about the interpersonal relationships in his wider family; that he had an ex-wife who did not think contact with Daniel was good for their daughter, and a daughter who was married and had recently had a baby, and with whom Daniel obviously wanted to have contact. Daniel talked about his cultural beliefs and practices, as well as family tradition, when he explained he *told his son that he didn’t want to be taken back up north when he died*. Daniel is Maori and traditional Maori protocol requires that the body of the deceased be taken back to their particular tribal land for the purpose of holding a tangi (funeral) and burial; each tribe (Iwi) within Aotearoa New Zealand has its own tribal area. Daniel is also indicating that his son will play a pivotal role in this decision after Daniel has died. This point is obviously important to Daniel as he repeats it twice in his narrative:

Daniel was saying that his home is down here now with his new wife Emily, and he doesn’t want his body to be taken away when he dies because then Emily won’t be able to visit him and see him.

This sentence refers to life beyond death, Daniel not only believes that Emily will be able to visit him, she will be able to see him, and in this way their relationship will be maintained. There are so many losses in Daniel's story, but the one thing he believes he will have forever is his relationship with Emily. It gives him something to hold on to when all else seems to be slipping away.

Up to this point, Daniel's narrative has centred on knowing he has cancer, what this means to him, and who he wants as companions in the next part of his journey. Now the narrative shifts to his understanding of why he has cancer:

He says that they broke up the blockage in his bronchial tubes, but it was cancer and he understands that this made it spread into his lungs.

Without realising it at the time I wrote my field-notes, I had also included an explanation as to why Daniel may have cancer:

I noticed that even though all the windows were open, and it was freezing, the house smelled very smoky. There were no ashtrays or cigarettes to be seen and neither of them smoked while I was there. Not sure if one or both of them smoke.

As an ethnographic researcher, I was paying attention to what was not said in Daniel's narrative and to clues provided by the environment, which would tell me more about these participants. Daniel and Emily did not smoke in front of me, but the house smelled of smoke, and I did not see an ashtray when I visited them at home. Crossley (2000) explains that meanings are held together by the use of the plot which contains judgements and valuations, heroes and villains. The public narrative (Somers, 1994): "Smoking causes lung

cancer”, assigns blame to the smoker. Daniel’s way of shifting any blame and establishing himself as morally acceptable, not the villain in the story, is by focusing on a medical procedure which he understands spread cancer to his lungs. Somers states: “To be sure, agents adjust stories to fit their own identities, and, conversely, they will tailor ‘reality’ to fit their stories” (p. 618). Daniel’s narrative identity (Somers, 1994) is carefully constructed to ensure that as the plot develops he is portrayed as an acceptable character, worthy of attention. By constructing this identity, he is entering into a negotiation with me as to how I might be expected to understand his story, as well as providing clues as to how I might be expected to react to his story (Norrick, 2000).

The final part of Daniel’s narrative was provided in direct response to my question asking how he was referred to the community team. This was the original query that triggered the narrative of Daniel’s diagnosis. In his narrative account, Daniel is unsure at first about who referred him to the team but then remembers it was his hospital social worker. From the way Daniel tells this part of his story, I am alerted to two things. Firstly, he does not see his referral to the team as significant in his process of diagnosis, and secondly, he places great value on his relationship with his hospital social worker. This was evident at the beginning of Daniel’s narrative, when I asked him to tell me about his referral to the community palliative care team; instead, he discussed his positive relationship with his hospital social worker. My need to address my research question is peripheral to Daniel’s need to tell his story about how he makes meaning from being diagnosed with cancer. Although referral to the palliative care team held little meaning for Daniel, it completed the story for me. It met my need as a researcher, not Daniel’s need as the teller of the story.

5.3.2 Billy's story

The next participant who shared his story about diagnosis and referral to the palliative care team was not recruited in the same manner as the first six participants (see Chapter Four, section 4.4.3). I was introduced to this participant and his wife by a man called Christopher who was a neighbour of mine and Billy's.

Billy's narrative account of diagnosis and referral to the palliative care team developed over a number of visits, as Daniel's did. Like Daniel's story, Billy's story helped me to understand that he felt hopeless when he was diagnosed and realised there was no treatment for his type of cancer. He spoke about dying, just as Daniel did. Whereas Daniel developed hope from the therapeutic narrative with his oncologist, Billy's story reveals that he developed hope in a deliberate attempt to prolong his life:

He said that if he thinks that he will die, then he is sending negative messages to his body. I said I understood this, but I wondered how he managed to balance hope with reality. He said that he is aware that the reality is that he has incurable cancer and that his prognosis is not good, but he wants to try to be positive about it.

Billy spoke about the interpersonal implications of his diagnosis, as Daniel had also done, and both of these participants spoke about protecting their loved ones from the implications of their illness. In a similar manner to Daniel, Billy's diagnosis was complicated by his existing medical condition. Both participants had secondary cancer by the time they were diagnosed, and both tried to explain why they believed they had cancer.

Billy explained that he only has one kidney and that he was born that way.

Daniel's narrative account does not appear to attach much significance to his referral to the community palliative care team, but Billy's story makes a direct link between his referral to the community palliative care team and his prognosis:

I asked him if he had been referred to the community palliative care team as this was part of my necessary criteria for participants. He said he had been referred not long after his diagnosis, when they were told there was no suitable treatment for his cancer.

5.4 Immediate Diagnosis

Elisabeth and Helen went to their GPs because both had found a lump. Their GPs immediately sent them for a biopsy and they were diagnosed with cancer. Once they were diagnosed, they were referred to the oncology department where they were both diagnosed with primary and secondary cancer (metastases).

5.4.1 Elisabeth's story

I arrived for my first home visit at Elisabeth and her daughter's home. They were sitting at the back of the house in the sun. It was a beautiful day and I pulled up a chair and sat with them. After I had gone through the process of explaining the research, Elisabeth began her story by setting the background. She had moved to the city to live with her daughter Penny, thereby leaving an unsuccessful and demanding relationship with her husband of 15 years, and gaining better access to health care. Elisabeth talked about being "sick", and when I asked her if she knew what was wrong, she said, "*No, I just felt really sick*". As her story unfolded I realised she was diagnosed with cancer before she moved to the city. In an attempt to clarify information in the narrative, I asked her if she was diagnosed in the city hospital and she replied, "*No, [in a small town] hospital.*"

In the narrative, Elisabeth uses past tense when she talks about her cancer diagnosis. Penny provides an alternative narrative that is woven into Elisabeth's narrative:

"Mum had lymph cancer but now she has it in her liver. Her kidneys are only working about 50% too."

Elisabeth, who heard what Penny had just said, adds:

"My chest is good, I had an x-ray of my chest from the front, and the back and the sides, and it's clear, there's nothing wrong with my breathing."

Penny attempts to expose the distorting information Elisabeth is providing by quietly saying to me so Elisabeth can not hear:

"It's probably her heart that makes her feel short of breath."

When we begin to discuss treatment, Elisabeth elaborates on the plot by providing information about other past events.

Elisabeth adds, "I used to have lumps in my neck. I had to go into hospital to get a biopsy because I had a lump on my neck and one on my shoulder." She pulls her scarf away from her neck and shows me where the lump used to be. "It's gone now, though," she says. "The one on my shoulder is much smaller too, since they did radiation." I say that I'm glad the radiation helped. Elisabeth then says, "After they did the biopsy they told me that I had cancer."

Although Elisabeth has provided the information that she was told she had cancer, if we look at how this revelation fits into the chronological events it actually comes before her comment, *"It's gone now, though."* These events are chosen and presented in this order because they reinforce Elisabeth's point that cancer is in the past. Elisabeth then changes

the topic by talking about quality of care. Elisabeth is providing a story, the plot line of which is, "I used to be sick, but now there is nothing wrong". As soon as Penny gets the chance, she provides me with a different storyline: "*I've been told that Mum only has this side of six months left.*" In Penny's plot line, Elisabeth has secondary cancer and is seriously ill.

Each character is providing me with their understanding of Elisabeth's current prognosis, and in my interpretive relationship (Crossley, 2000) with the narratives, I begin to understand the competing needs of the tellers. Elisabeth wants to believe that she will live. Penny wants Elisabeth to accept that she is dying, but she does not want to be held responsible for Elisabeth's awareness:

"Well, I sure don't want to live with a whole lot of tension in the house, which is what will happen if I have to tell her."

Norrick (2000) discusses the relationship between an initial story and the response story. She suggests that response stories develop as an audience responds to the initial story. The audience's purpose is to explain how they understand the initial story and to provide comment on it. Norrick argues that response stories or the co-narration of stories works to establish rapport, and this rapport is developed because of the tellers' agreement on point of view and the details which are described. Norrick argues that when co-narrators disagree about points or details in the story they enter into negotiation to determine who has the right to develop the point of the story. Negotiation ends by the characters reaching agreement, and by the end of the story, rapport is established. Although I can apply Norrick's theory to a point, it does not account for the continuing lack of congruence

between Elisabeth's and Penny's narratives. It is possible they have agreed not to expose the existence of the cancer.

In Crossley's (2000) article on terminal illness, he discusses how people who have been diagnosed as HIV positive rebuild meaning in their lives through the use of various forms of narrative. Whilst reading this article, I came to understand that Elisabeth and Penny were actually telling me quite different narratives, not co-narrating one cohesive story. Elisabeth's story fits Crossley's definition of a "normative narrative", or what Frank (1995) calls a "restitution narrative". Penny's story fits Crossley's definition of a "story of loss" or what Frank refers to as a "chaos narrative". Crossley (2000) states that Frank (1995) refers to chaos narrative as a type of "anti-narrative".

In the interviews that Crossley (2000) conducted with HIV positive men, he found that some of the participants displayed a "temporal orientation" which served to minimise or actively deny the impact of their diagnosis on their future. This orientation is identified in a person's narrative by their refusal to relinquish their view of the future, or to accept the inevitability of their death. In the story Crossley presents, the character "John" denies knowledge of his diagnosis, just as in this research, Elisabeth does throughout her narrative. Crossley argues that the use of a normalising story (such as Elisabeth's), helps the person to maintain a sense of control and order in the light of imminent chaos. Further, Crossley argues:

These modes of formulating positive meaning help the individual to retain, in Lifton's (1968) terms, a sense of 'symbolic immortality'. What this

basically means is that the individual, in the face of inevitable biological death, needs to maintain an inner sense of continuity. (p. 153)

By not accepting or acknowledging her imminent death, Elisabeth has indeed told me a narrative that contains no mention of death or demise, and a narrative that contains a future time:

Elisabeth then said, "When we get some money together, we are going to open this room up and make it lighter."

In contrast to Elisabeth's story of loss, her daughter Penny's narrative is primarily about Elisabeth's diagnosis and imminent death. Penny even provides "proof" of this impending demise:

She got up and went over to a dresser and brought back a piece of paper. It was quite wrinkled as if it had been used a lot, and it was folded in half as if she didn't want Elisabeth to see it. As she put it in front of me, she said, "This is a list of what she eats."

By showing me what little Elisabeth has eaten for each meal over the previous few weeks, Penny hopes I will understand her point of view.

As in the cases already presented, the type of narrative plot that is developed tells us a lot about the characters' sense of hope. There is no hope present in Penny's narrative of loss, but there is hope present in Elisabeth's narrative, she has been cured before, and believes she will be cured again as the cancer has already shrunk because of the radiation treatment. Where Elisabeth's narrative is quite different from the narratives analysed so far, is in her refusal to acknowledge her current diagnosis, or prognosis.

5.4.2 Helen's story

As I have previously mentioned, Helen found a lump, went to her GP, and was diagnosed soon after with metastatic breast cancer. On my first visit to Helen's home, I also met her husband Chris. I explained the research to them and they both signed the consent forms. I explained that I wanted to understand the process of Helen's referral to the community palliative care team, and I wanted to know about her experiences with palliative care. She told me that she was really quite boring, and that she had just learnt how to live with cancer. Later on, as I got to know Helen, we would often refer back to this statement. She made it at a time when she was not having any treatment, was still working, and did not talk to many people about her cancer. She had learnt how to manage the low level of pain she had at the time, and often thought of her cancer as being in remission. Chris decided to leave us to talk, and Helen and I sat in the dining room overlooking a beautiful garden as we began to talk about her initial diagnosis and referral to the palliative care team.

Helen establishes herself as the main character in the story in her narrative. She represents herself (Lawler, 2003) as proactive when she was diagnosed with cancer and as not concerned about having a mastectomy:

“Some people would freak out if they found out they had to have a mastectomy but I just said, ‘Whip it off’. I really didn’t care.”

In the third column of my field-notes, I noted my surprise at Helen's statement. I noted that it was quite different to what I had expected anyone with cancer to say. I was more in tune with the public narrative (Lawler, 2003), that it is a shattering experience to be diagnosed with cancer. However, Helen's statement is also a very effective teller strategy

(Norrick, 2000), she gained my attention and engaged me in her story. As a preface for the rest of her story, she provides a stark contrast between her feelings at her initial diagnosis, “*I just said, ‘Whip it off’, I really didn’t care*”, her feelings about metastatic cancer, “*I was devastated; I thought that was the end, I cried for about three days solid*”, and her later diagnosis with a brain tumour:

“I thought, well, I have beaten every thing else, this is it. You just can’t fight brain tumours. I went home and cried and cried. I knew it was the end; I prepared to die.”

The final contrast is provided when she says:

“So he did another MRI, and sure enough, it was exactly the same size as it had been. So I came home with a new lease on life, determined to get on with living.”

Each of the episodes in her story provide insight into the heart-wrenching complexity of dealing with cancer as well as adding to the overall plot of the story. Helen adds emphasis to the later impact of being diagnosed with extensive secondary cancer by stating: “*I had always been so well that my doctor didn’t even know who I was.*” This provides a stark contrast to the statement:

“I had obviously had cancer for years, but I always felt so well. Apparently it takes about seven years for a small tumour to grow; well mine was huge so I had obviously had it for years.”

Notice the change from the certainty of the first statement, “*I had always been so well*”, to the doubt and uncertainty in episode two, “*I always felt so well*”.

Helen also adds clarification which illuminates why she had shifted from “not caring” about being diagnosed with cancer, to feeling devastated:

“It wasn’t the liver and lung cancer that worried me. . . . It was the bone cancer that threw me, because it meant a whole change of lifestyle. We used to go away skiing all the time, and I knew that I wouldn’t be able to do that anymore. I also used to work in the garden a lot and used to be able to haul huge wheelbarrows of mulch and stuff. Now, suddenly, I couldn’t do any of those things. I had to change my life.”

This statement explains the meaning of physical limitations for Helen and what she regards as necessary to her quality of life. Skiing trips had been an important part of Helen’s family culture; how she and her husband had had quality time with their young adult children. The idea of a family that goes on skiing trips is also culturally laden as it holds class implications. Because of the cost of this sport, it is often considered the sport of the middle and upper classes. This comment, therefore, provides a little more information about Helen’s cultural identity. It is followed by Helen’s reflection that she used to be able to “lug loads of mulch” around in wheelbarrows. She used to be strong and independent, and enjoyed her own quiet company in the garden. Gardening had been one of Helen’s passions, and we sat together week after week admiring the years of work she had put into creating her own garden paradise.

The way Helen’s narrative is recounted, places the emphasis on her psychosocial transformation at the time she realised the implications of her secondary cancer. In this respect it is quite different from the preceding narratives.

Helen was diagnosed as soon as she had symptoms, so her narrative is quite different in this regard from the narratives told by Jack and Allan, and by Joan. Their transformation began when their health deteriorated, and diagnosis was perceived as validation. Helen had not had any existing medical problems, so her story is also quite different from Daniel's and Billy's. Daniel's transformation began at his diagnosis, but his realisation of how much the diagnosis changed him occurred in the family meeting. Billy's transformation also began at diagnosis, but gained momentum when he was told there was no treatment for his cancer. Helen acknowledged her diagnosis and the implications of it, so her story is quite different from Elisabeth's. By not acknowledging her diagnosis, Elisabeth's process of transformation was stalled. We can, however, see her daughter's process of transformation and the resulting chaos.

The beginning of Helen's story is what Crossley (2000) calls normalisation, which, he suggests, is similar to Frank's notion of a restitution narrative, referred to earlier. Frank (1995) argues that there is a certain amount of denial in a restitution narrative. Helen next discusses her secondary diagnosis. Crossley refers to this as the story of loss and explains that this would fit with Frank's chaos narrative. This sense of chaos does not last long, however, as Helen actively engages in treatment, what Crossley calls the conversion/growth story which he likens to Frank's "quest narrative".

My initial request was to know about Helen's referral to the community palliative care team. It is interesting that the first mention of the team in Helen's narrative is not related to her referral, but to her decision to come off the palliative care team's books. It seems that

she no longer classes herself as in need of palliative care at that point. Later in Helen's story, when she is experiencing a significant level of pain, she again refers to the palliative care team saying:

“I called the palliative care team and they got me onto morphine. It's really hard to get back on their books once you've gone off them, so in future I will just stay on their books.”

My interpretation of these comments about the palliative care team is that Helen sees contact with the team as necessary only if she has active symptoms such as pain.

5.5 Second Diagnosis of Cancer

The final two narratives are from participants who had been diagnosed with cancer at a previous point in their lives, so when they developed symptoms, their respective GPs did not hesitate to refer them back to the oncology department. Their diagnosis with terminal cancer did not, therefore, coincide with their earlier diagnosis with cancer, so their stories differ a little from the previous narratives. This is Alice's story of her diagnosis.

5.5.1 Alice's story

I arrived at Alice's place for my first visit. Her fiancé was at home with her. In response to my questions about her referral to the community palliative care team, Alice immediately began to talk about her move to the city and how she had never had this type of support before, because they did not have a community palliative care team where she was living previously. She spoke of her contact with the palliative care team very positively. I asked

her to explain why she was referred to the team, and Alice talked about her most recent diagnosis of cancer.

Alice's account begins with her move to the city, and her positive experience of being referred to the palliative care team. She then tells me that she is preparing boxes for her children to be given to them when she dies. Next she tells me she only has two months to live and that she and Dennis are getting married. Her next comment is about the success she is enjoying in her job, the beginning of health symptoms, including a suspected cold, and her subsequent diagnosis with cancer. I had been at Alice's place for about 15 minutes and had been presented with a multitude of culturally-laden facts in succession with little detail about any of them. I found it quite difficult to listen to the facts that were literally pouring forth from Alice, as I had no context in which to locate them and understand them. This is symptomatic of a listener's experience of hearing chaos narratives (Frank, 1995) where the information being provided is almost an anti-narrative, or narrative wreckage. There is no plot to the narrative at this point, but there are characters who have been introduced: Alice's two children, her fiancé Dennis, the palliative care team, and work associates. There is also transformation evident in the facts she provides, but no mention of what any of these facts mean to her. As the listener, I can attribute meaning to the facts, but as a researcher, I am interested in what these facts mean to Alice. Crossley (2000) states, "It is true that individual 'events' and 'facts' take on meaning only when they are placed in a particular 'organizing scheme' or 'narrative framework'" (p. 56). To explain what is happening to a person who narrates a story without a narrative framework, Crossley (2000, p. 56) refers to the work of Martin Heidegger:

The existentialist philosopher Martin Heidegger (1962) developed his concept of 'Angst' (a kind of intense anxiety or dread) to characterize the feeling and experience of disintegration that can, at times, be radicalized and generalized in a person's life to such an extent that the whole complex of projects in which an individual is involved becomes problematic. The experience of angst is like that of vertigo, when a person is brought face to face with the presence of an abyss and the absence of anything holding one in place and anchoring one's actions (Cooper, 1990). In this kind of existential crisis, often brought about by seriously traumatizing events such as bereavement and other forms of loss such as . . . terminal illness . . . nothing makes sense anymore.

When this happens, we lose any sense of connectedness and sense of who we are. Life events are often peeled back to their basic facts and spoken of as meaningless sequences of events that a person must endure to get through life on a daily basis. Time becomes meaningless (Crossley, 2000). Drawing on this understanding of narrative structure can provide an indication of the meaning behind Alice's presentation of facts, and the level of trauma she is experiencing about her diagnosis.

Alice's story is not cohesive (Lawler, 2003) and it does not make sense of random happenings (Kohler Riessman, 1994). Events that Alice selects to recount do not add logic to an overarching story (Somers, 1994). In fact, events are not presented in any particular sequence. Crossley (2000) argues that events become episodes because of the order they are presented in, and as each episode unfolds, it contributes to the overall plot of the narrative. Ricoeur's (1991) concept of synthesis and, therefore, emplotment is almost absent from the events Alice talks about. As discussed earlier in this chapter, Lawler (2003) argues that narratives have a beginning, middle, and end; they arrange events in a logical order so that one event leads inevitably to the next. She also argues that there must be a

point to the story, and the process of telling the story creates a narrative identity. Alice has not told me a narrative of diagnosis as the other participants have. In not being able to create a narrative about her diagnosis, Alice has provided a lot of information about her inability to make meaning from her diagnosis. The lack of narrative structure in Alice's account provides a clear indication of the level of distress Alice is experiencing and her acute awareness of impending death.

This type of narrative structure continues throughout the rest of Alice's account. She provides more facts: she was referred to oncology by her GP, there is nothing they can do this time, and if they had not put the stent in when they did, she would have died. She carries on with a discussion about where she wants to die, and becomes quite emotional in this discussion. Then she begins to discuss her funeral and the coffin she wants, and that she wants to make a video. Without any lead in, Alice begins to discuss a friend who is about to have a baby, and then she discusses her wedding. Alice raises a point in this section of her narrative about the "news worthiness" (Norrick, 2000) of her story. She introduces a romantic notion of the bride in love marrying her fiancé just before her death, and the people in the community who are going to organise and pay for the event. I wrote the following comment in my field-notes at the time:

Think about the symbolism of marriage, two participants out of five [interviewed to that date] have got married when they knew they were going to die, what does this act mean to them? What does it mean to their spouse? Think about how society views this sort of thing. Alice is right; it is regarded as 'news worthy'. It is like the classic Romeo and Juliet where love and death are inextricably entwined creating a romantic tragedy that has influenced people for centuries.

At the time I wrote this comment, I had only recruited five participants, one of the five had just married and another one was about to marry. I had a total of eight participants whose data I could use by the end of the fieldwork: Alice was getting married after her diagnosis with incurable cancer. Two other couples had moved their weddings forward because of the likelihood that their experience of illness was cancer, but their diagnosis was not confirmed until days after their wedding. There was also one participant who had been about to get married and decided to postpone it.

Crossley (2000) writes about the two dominant themes that appear in narratives, those of power and love. She defines love as the “desire for connection and dependence” and argues that love is one of the most fundamental driving forces in life. Spiegel and Diamond (2001) suggest that awareness of an incurable illness that will shorten a person’s life may result in a renegotiation of life priorities. Getting married to the person they were closest to when they were diagnosed may be Alice and Dennis’s, as well as the other participants’, way of getting the most out of the time they have left. It may also be a way of ensuring that they have a committed partner on whom they can depend as their illness progresses. Getting married also gave Alice something to focus on in the future that was positive and meaningful when all else seemed to be spoken of in negative terms. It may, therefore, also serve to provide some hope for Alice at a time when she was feeling hopeless.

5.5.2 Tom’s story

When I arrived for my first meeting with Tom and his partner Michelle, it was raining but their house was warm. Tom was very thin and frail and moved with great difficulty. He

also had trouble speaking, because he originally had an oral cancer. Tom settled himself on the couch, where he spent most of the day. I recapped the information they had given me on the phone prior to this meeting. I said that I understood Tom had been referred to the community palliative care team when he found out he had secondary cancer, and the referral was done by the public hospital oncology department. He and Michelle confirmed this information. They explained that the nurses from the community palliative care team were visiting them at home regularly and that the visits were really good. I outlined the research to them and we went through the consent forms which they then signed.

Tom's narrative begins with an account of his first diagnosis with oral cancer and his subsequent belief that he was cured. This preface sets the context for the rest of Tom's story. As the listener I am, of course, aware that Tom's cancer has come back and that he is now dealing with incurable cancer. I know from his statement that he thought he was cured, and from the sad tone of his affect, I can tell that he has lost a certain amount of hope. When Tom leans forward for a cigarette, he tells me that his cancer was not caused by smoking. His comment is interesting in that it contradicts the public narrative that smoking causes many of the oral cancers. There has also been research carried out that indicates that his type of cancer is indeed caused by smoking (Bornstein, Klingler, Saxer, Walter, & Ramseier, 2006). As I am also collecting observational data, I note that the packet of cigarettes Tom picks up has "Smoking causes death" written in bold across the top. The fact that Tom makes this statement actually tells me that he is aware of the public narrative that smoking causes cancer. Like Daniel, Tom is attempting to address the issue of blame,

thereby, establishing himself as a morally acceptable character in his story. As discussed in Daniel's story, narratives contain judgements and values (Crossley, 2000).

The second component of Tom's story flows on as a natural progression from his diagnosis. He discusses pain symptoms which led to his most recent diagnosis of cancer in his spine. He explains his confusion about the pain, and his willingness to believe that it is back pain. Tom's belief that his cancer was cured was very strong, so even in the face of what was to become debilitating pain, he did not seriously consider that it was caused by cancer. Tom had held a strong belief that if cancer ever did come back, it would be closer to the original site. This belief enabled Tom to avoid engaging with the question, is this cancer? Although I know that the point of this story is that Tom has now been diagnosed with cancer of the spine, Tom is telling me about his process and his surprise at this current diagnosis. He is inviting me into his journey so that I might understand his disappointment and confusion when he was diagnosed.

Next, Tom lets me know that the only reason he and Michelle saw his oncologist was because he had history of cancer. He does not say that it was because he or anyone else thought he might have cancer. This part of his story is introduced as if in answer to the question, "And then?" that Ricoeur (1991) suggests is indicative of the way in which time is embedded in the episodes. As Lawler (2003) explains, one event leads inevitably to the next event as the story is emplotted; the way episodes are linked implies that earlier events somehow cause later ones. This idea provides some insight into this part of Tom's story when Tom discusses the wait they had to endure because of the radiologists strike. What

significance does Tom attach to the strike? Does he believe that his cancer progressed when he was “waiting around” for results? Or is Tom merely indicating that he and Michelle were left wondering for quite a long period of time, and that not knowing what was wrong was difficult?

Tom’s narrative about diagnosis with his current occurrence of cancer reaches its ultimate point when he says he was told *there was a spot in the bones that looked like it could be cancer*. He does not need to add anymore about his diagnosis because he is aware that I already have the information about his current state of advanced cancer. Like Alice, this is Tom’s second diagnosis with cancer. Alice did not have any treatment at the time she was diagnosed with metastases, and Tom had only one treatment of radiation. Therefore, neither Tom nor Alice talk of treatment with hope, as the previous participants do in their narratives. Tom says his oncologist made the comment that *they still have a few things up their sleeves*, which may have been intended to create hope for Tom. This comment was apparently made to the majority of the participants by a variety of oncologists (see Chapter Nine, section 9.3.1, for further discussion). The research by Del Vecchio Good et al. (1994), referred to earlier, examined how oncologists attempt to create hope by focusing on the immediacy of treatment and how they deliberately create ambiguous endings. The comment made by Tom’s oncologist is easily categorised as ambiguous as it does not indicate what options Tom has or when these options may be discussed or acted upon. It does, however, indicate to Tom that there is more that can be done to extend his life.

During the visit, I asked Tom and Michelle about Tom's prognosis. Michelle said they had been told Tom was terminal. I said I was surprised as I had never heard an oncologist use the word "terminal". When I questioned Michelle and Tom further, Michelle said, "*No, they didn't say it directly, but they kind of implied it.*" Tom then said to Michelle, "*You are the only one who has said the word terminal, but they did imply it.*" Even if oncologists statements are ambiguous, as Del Vecchio Good et al. (1994) suggest, patients and families will extrapolate meaning from the information they are given and will develop their own understanding of the prognosis. Developing an understanding of how much time they had left seemed to be very important for participants. This issue is explored in further detail in Chapter Eight (see section 8.7). Once they knew what kind of time frame they were looking at, participants, such as Alice and Tom, set themselves some new goals which they hoped to achieve. Research indicates that oncologists tend to encourage patients to pursue goals which are enjoyable (Del Vecchio Good et al., 1994).

Scheier and Carver (2001) suggest that new goals are set by people once they realise and accept that a previous goal they had was unattainable. Some of Tom's goals, prior to this diagnosis, were to live a long life, to see his children grow up, to marry his new partner, and to buy a new home together. Alice's goals prior to diagnosis were to live to see her children grow up, complete her teaching qualifications, and then marry her fiancé Dennis and save for a home. Once they were diagnosed with secondary cancer, both Alice and Tom realised their goals were unobtainable, but rather than give up in despair, they each set themselves new goals. Alice and Tom both set themselves "future time" goals which they

drew on to give themselves hope. Alice had her wedding to look forward to. Tom was looking forward to the Rugby World Cup in 2007 and had already bought his tickets.

In his narrative, Tom makes the comment, *“I’m a good staunch kiwi bloke, I’m not about to roll over and die.* This comment is culturally laden and creates a narrative identity based on a moral judgement, that Tom is a “good, staunch kiwi bloke”. It builds on the cultural and public narrative that “kiwi blokes tough it out and do not die”. In his discussion of stereotypical gender prescriptions, McMaster (2001) states “Real men are tireless, invincible, and keep working regardless of personal or health risks” (p. 114). The issue of gender role socialisation is discussed further in Chapter Six (see section 6.6). Suffice to say Tom’s socialisation encouraged him to develop clear patterns of thinking that are classified as typically masculine in nature.

Tom also acknowledges that underneath the bravado, he accepts the reality of his situation when he says, *“I’m aware that I won’t survive this cancer, I know it will kill me eventually.”* It is interesting that just after Tom says he knows his cancer will kill him, he alludes to his masculine nature again when he says that it is important for him to keep fighting. McMaster (2001) suggests that gender socialisation encourages men to regard any expression of emotions as a sign of weakness and vulnerability. As Tom’s story is emplotted, he has created a narrative identity of a man who against all odds is going to fight cancer and live longer. He has established some goals for the future, which he indicates he has every intention of achieving. Tom’s narrative account provides a lot of information about the events that occurred as Tom was diagnosed with secondary cancer,

yet there is little spoken about his feelings about this diagnosis. The reason for this may be attributed to Tom's beliefs about appropriate male behaviour in New Zealand culture.

There is no doubt that Tom has been transformed in the story he tells; however, his transformation is more covert than overt. Understanding the meaning of his diagnosis is primarily left up to the listener to interpret. My interpretation as the listener is heavily influenced by my observations. Although I hear Tom saying that he is staunch and will fight this cancer, there is little doubt for me in Tom's presence, his emaciated body indicates he has "little fight left". The incongruence between the masculine ideal Tom is clinging to in his narrative, and the physical deterioration of late-stage cancer, provide a stark contrast.

5.6 Conclusion

The area of enquiry identified in the first research aim, and explored in this chapter, was participant's awareness of their diagnosis. The natural extension of this line of enquiry was whether participants knew that they were being referred to the community palliative care team because their diagnosis indicated a fairly bleak prognosis.

In the process of analysing the eight participants' narratives, a multitude of issues have been raised and discussed. In creating a narrative account of their journeys so far, participants had a vehicle to make meaning of their experiences up to the point of diagnosis and beyond. As the participants reconstructed their narratives, they were able to give voice to their grief and to the losses they had already encountered. They each spoke about life-

changing episodes that contributed to a sense of transformation. Although the process of diagnosis was different for all of the participants, the concept of hope became apparent in each of their stories. It was a theme that developed in the process of analysis and became dominant throughout the chapter. The similarities and differences in the participants' stories revealed a lot about the circumstances in which hope can be developed or diminished. Participants' awareness of their diagnosis, in every case but one, provided a contrast for the exposure of therapeutic narratives, which actively diverted participants' attention away from acknowledging endings. The one exception was Elisabeth; by actively denying the impact of her diagnosis on her future, Elisabeth existed in a state of symbolic immortality.

Two other categories to emerge through the analysis were "power" and "love". Power dynamics were most evident in the participants' journeys to diagnosis whilst negotiating access to specialised health providers. Love in its most romantic guise, marriage, was a somewhat surprising topic in half of the narratives. It may, however, be indicative of goals, hopes, and dreams that participants actively renegotiated after their diagnosis.

In answer to the question, "How do individuals and families make meaning from the process of being referred to palliative care?" my reply is that they do not necessarily make meaning from the process of initial referral to the community palliative care team. At the point in participants' journeys when they were referred to the palliative care team, seven of the eight were not close to death. All of the participants were involved in, or soon became involved in, some form of treatment. They pursued avenues that provided hope and

engaged in therapeutic housekeeping which provided a somewhat tenuous distraction from the awareness of their diagnosis. Referral to the hospital palliative care team, which occurs much later in the disease process, may be viewed quite differently by the participants. Exploration of the participants' narratives highlighted the meaning-making process that they engaged in to understand their diagnosis which, in turn, led to their referral. Participants spoke of the palliative care team as providing support, but they spoke of their oncologist as the person who provided hope.

Chapter Six

A Changing Landscape

*Ethnography, the process of understanding people's geographical experiences, is not easy or streamlined, and often results in a 'fumbling for meaning' which occurs in the context of 'an intensely consuming personal experience'.
(Rowles, 1978, p. 176)*

6.1 Introduction

This chapter explores the participants' journeys after diagnosis, in particular the incorporation of their diagnosis into their existing cultural identity. The participants involved in this research made significant life changes after diagnosis with cancer. Many of them left work, a place which gave them a certain sense of identity. Some of them withdrew from groups and activities they had been involved in. Some of them withdrew from social circles and friends. All these external networks provide information about the participants' identities; they add rich, textured layers to the understanding of their previous place in the world. In place of these networks and support systems, the participants found themselves involved in a new world. As their identity shifted, their priorities also changed (Spiegel & Diamond, 2001) and their lives were significantly and irreversibly altered. The participants developed an altered sense of identity, as people with cancer, and began to progressively identify with other people who also had cancer. They also began to occupy new places which developed meaning for them through interaction and enculturation. Participants' interaction with these new places is explored by considering the symbolic meaning of cultural markers.

Cultural markers or identifiers are imbued with meaning for cancer patients, and are used to recognise other people with cancer and negotiate access to certain places. Cancer patients develop a sense of “rights” in relation to these cultural markers. On the whole, these cultural markers are “place” specific, in that they will only be recognised in certain locations and by certain people. The places explored in the current chapter are: Cancer Society support groups, the public hospital accident and emergency department, the hospital car park, and the Cancer Society’s “Look Good Feel Better” workshop. Further exploration of the locations that participants occupied is discussed in Chapter Seven.

The current chapter provides a chronological exploration of the participants’ journeys through place and time, from diagnosis to the end of life. My initial meeting with all eight participants was in their homes. As the fieldwork progressed, I also spent time with participants in the oncology department, the chemotherapy suite, hospital wards, general practitioner offices, the x-ray and nuclear medicine departments, operating theatres, the recovery room, participants’ local areas and shopping centres, and multiple other sites of relevance to participants. Within this chapter, I explore the places that had primary meaning for the participants. This background serves as a cultural context to the journey participants undertook after diagnosis: a journey involving a rite of passage that moved them from one social category to another, a journey during which they left certain places and connected with other places. This journey is considered in light of the developing relationship between the researcher and the participants, and, consequently, the mutual exploration of the meaning of place. The relationship between place and identity, as well as the gendered nature of place, will also be explored in an attempt to understand the cultural

milieu of the participants' world. The role of geographical fantasy, which enabled participants to occupy multiple sites during a time of increasing physical limitations, is also considered.

Rowles (1978, p. 176) suggests that in ethnography the process of understanding people's geographical experiences is not easy or streamlined, and often results in a "fumbling for meaning" which occurs in the context of "an intensely consuming personal experience". The research journey which occurred alongside the participants' journeys was an intensely consuming experience for me. In the process of making sense of this experience and the resulting data, I did, at times, feel as if I was "fumbling for meaning". This led me to explore a number of articles from a range of disciplines, including humanistic geography, psychology, geography and urban planning, and feminist studies. The knowledge gained from this literature provided multiple lenses by which to understand the data about the places participants occupied and eventually led to the grounded core category of "time and place".

6.2 Participants' Home and Sense of Time and Place

Throughout the fieldwork, I visited participants in their homes and explored the meaning of home for each of them. In a similar manner to that described by Kottak (2002), I asked participants about their home environment. The questions I asked were about the history of items in the home, the people in photographs, how long the participants had lived in this location, and where else they had lived. I also asked questions about how the participant was managing at home and what, if any, support aids they had been given. Many of the

participants would have benefited from the use of support aids, such as back boards, recliner chairs, shower stools, and commodes, but none of them had been given any of these (I discuss this issue further in Chapter Nine, see section 9.4.2). I also discussed the home environment with members of the ill participants' families. As each of the family members and participants provided information about home, I developed an intimate, culturally-bound sense of the places that participants embodied and called home.

I recorded my first impressions of participants' homes in great detail in my field-notes. These initial field-notes provided descriptive details about the material contents of these "bounded locations" (Kenworthy Teather, 1999), and they also contained initial impressions of these places derived from not only the material objects but also the smells, the organisation of the home environment, and the people who occupied, or had occupied, these spaces. The context, contents, and arrangement (Richardson, 2003) of participants' homes provides information about the participants' identity. In total, these field-notes consist of approximately 25 pages of descriptive detail, which is, unfortunately, too lengthy to reproduce within this chapter. Descriptive detail provides a glimpse of the participants' culture, but it does not tell us what these places mean to the participants, or how they reflect the participants' identity. However, the details of participants' homes will inevitably be drawn on as I consider their occupation of different spaces. This background information contributes to my understanding of the existential meaning of "place" for each of the participants.

As I got to know the participants, I realised that their occupation of certain spaces was a direct result of their diagnosis and illness; they were, as Rowles (1978) suggests, in a changing relationship with their environment due to physical limitations. This realisation is explored by drawing on the metaphors of “journey” and “rite of passage”.

6.3 Rite of Passage

The process of recognising ill health, gaining a diagnosis, and the reduction in the number of places that participants occupied can be explored by using the metaphors of “journey” and “rite of passage”. Drawing on a theoretical framework derived from the field of anthropology, the rite of passage model offers a structure for the dying individual’s transition from life to death (Froggatt, 1997). Arnold van Gennep (1909, as cited in Froggatt, 1997) was the first to describe rites of passage and proposed that they consist of three processes, separation, transition, and reincorporation. Kenworthy Teather (1999) refers to this same process as “a journey through time and space”, which is often marked by crises. She also suggests that these crises can be regarded as a rite of passage, and focuses on passages as being transitional in nature. In a similar manner, Moss and Dyck (1999) explain that a rite of passage is an act which marks the movement of a person from one social category to another. In applying the rite of passage model to end-of-life care, Froggatt (1997) acknowledges the implicit and explicit boundaries which are mediated by end-of-life care models, such as hospice. She suggests that the hospice model obscures the life and death boundaries because it shifts the focus away from the medical model of cure or prevention and integrates the two categories of life and death. The shifting of boundaries which occurs during the life/death transition serves to highlight the role of time and space

during a rite of passage. The diagnosis received by each of the participants was the catalyst for their symbolic acts of detachment from their current way of living. During the journey from life to death, the terminally-ill individual exists in a temporary liminal state (Froggart, 1997; Frommer, 2005; Kelly, 2008; Thompson, 2007). This liminal state is referred to as a state of “living loss” (Kelly, 2008); a state of uncertainty and alienation from normal life (Thompson, 2007).

Each participant’s journey through palliative care began with a crisis (see Chapter Five), the diagnosis of incurable cancer. This crisis was the catalyst for the first of the three stages in the rite of passage model which van Gennep (as cited in Froggart, 1997) outlined, “separation”. In the rite of separation, the individual’s behaviour signifies detachment from places they previously occupied resulting in a corresponding shift in their social status. Jack and Alice left full-time employment permanently; Daniel left his full-time workplace, but as he missed his workmates and the sense of purpose that work gave him, he began to spend time with them during work hours. Participants who maintained some connection to their work place significantly reduced the amount of time spent in these places. Tom, Helen, and Billy were all self-employed, and their rites of separation led to each of them spending less time in their workplaces. Leaving their place of employment, or reducing the amount of time spent in their workplace after such a diagnosis, is considered, in New Zealand society, as a recognisable and justifiable response for people to make under the circumstances. It is often the act that signifies the beginning of their rite of passage from the social category of “able-bodied member of society” to being a person who dwells on

the fringes of the world they were previously immersed in: a person who is defined in current rhetoric as “a person living with cancer”.

A person who is living with loss, living with the knowledge of their impending death, living with cancer, is in what van Genep (as cited in Froggatt, 1997) referred to as the transition stage, “the limen”. In this temporary liminal state, the participants were detached from wider society, marginalised, and isolated to varying degrees. Two older participants, Elisabeth and Joan, had already begun a rite of separation when they retired from work around the time they both became ill. When I met them they were both in the rite of transition. They had withdrawn from their usual social circles and existed in a state of liminality. Elisabeth had left her husband, who was abusive, and had moved to the city to live with her daughter Penny, her grandson Marcus, and her son-in-law Ivan. She spent all of her time at home with Penny, and only went out to go to the hospital or doctors’ appointments. Joan was so ill by the time she retired from work that she never ventured far from home. In the years between her surgeries, she had met Bill and they had spent some time at his place on the coast which she enjoyed. Eventually, though, Bill moved to the city and looked after Joan at home. They did not go out often unless it was for hospital appointments. Within the transitional liminal stage, all of the participants withdrew further as time progressed, until they had very little contact with the social world. The contact they did have was with immediate family members and health professionals.

Engagement with health services resulted in participants spending time in new social spaces, namely the hospital oncology department, hospital wards, and the main city

hospice. They existed in a temporary liminal state moving between their homes, the hospital, and a limited number of social spaces. Kelly (2008) refers to this state as being a “liminal state of uncertainty”. It is a transitional state in which time is unstructured, where participants know that their existence is impermanent, where they hold the often unspoken knowledge that this state will only end when treatment options have been exhausted and their bodies have deteriorated to the point where death is imminent. Drawing on van Genep’s rite of passage model in end-of-life care, Froggart (1997) explains that it is only after death that the rite of reincorporation is enacted symbolically through funeral, tangi, or memorial rituals. Family members also experience the rite of reincorporation as they grieve and gradually rejoin society. Although all three stages of the rites of passage model are explored in the current study, it is the places within which the liminal state of transition occurs that is the focus of the next two chapters, Chapters Seven and Eight. Within these chapters, I explore the places that participants had in common, such as the hospital, and consider the meaning of the spaces participants occupied within the hospital. I also noticed in the analysis of the data that participants often spoke about places that held meaning for them; this included their current home environment as well as other places that were special. Understanding the meaning of these places was only achieved by getting to know the participants.

6.4 Subjective and Interpersonal Understandings of Place

Rowles (1978) suggests that in order to understand the meaning of place, the researcher has to first get to know the research participant. He argues that by getting to know participants, our knowledge of their environment shifts from being subjective to a deeper interpersonal

understanding. He explains that gaining interpersonal knowledge requires a level of immersion in the daily lives of the people being studied, an open, giving, reciprocal relationship. Rowles (1978) also suggests that by getting to know people well, a “special sensitivity” to their “geographical experience” is developed:

Together we may develop a shared awareness, almost communion, from mutual exploration. In such a relationship there is constant feedback as each of us uses the other as a referent in exploring ‘hypotheses’ we develop about each other. More than revelation is involved. Creation of a nonthreatening milieu for interpersonal dialog facilitates the development of commitment involving, in a sense, a becoming of the other. Thus I come to know [them] because I know myself and [their] experience becomes a part of mine. (p. 175)

As developing an open, reciprocal relationship with participants is a component of ethnographic research, it became easy for me to share my own experiences of place with the participants. When participants spoke about places that were special to them, I naturally thought about similar places I had known. This sharing led to an interpersonal understanding of the meaning of the places participants occupied. Achieving a sense of communion through mutual exploration of places was easier with some participants than others. Many of the participants had lived in the same city as I had for an extended period of time and lived in suburbs that I knew well, this aided the development of our mutual connection about place. However, there were two participants with whom I was unable to develop a connection to place which resulted in less being discovered about their identity.

6.5 Participants’ Identity and Home Environment

Participants’ home sites provided the context within which I developed a deeper understanding of their cultural identity and the meaning of home for each of them, their

sense of place. Kenworthy Teather (1999, p. 2) suggests that the term “sense of place” refers to the interlinking of “place and meaning, an existential quality, difficult to define, sometimes shared by many, sometimes different for each individual”. These places develop meaning and people become attached to these and the memories of experiences in these places. The places that have meaning for people then become part of their identity. The place that is often referred to as “home” conjures up the most precious of such memories. Kenworthy Teather (1999, p. 2) suggests that “home” is the place that represents an “ideal melding of place, culture and beloved people”. To understand participants’ cultural identity, we, therefore, need to understand the existential meaning of the places they relate to and occupy, or embody, on their journey through life. I came to understand the places that held meaning for the participants by exploring many places through conversations, photographs, and other artefacts.

Building on the preliminary understanding I had developed of each participant’s home environment, I found through the process of coding the data that participants were often in a particular place within their homes when I arrived to visit. Certain themes began to emerge from the data, about which I then wrote memos. The memos tended to be about the places participants occupied within their home and the meanings that were attached to these places. The spaces seemed to reflect components of the participant’s identity. I noticed that other people in the family referred to this place as the participant’s space. I also became aware of the gendered nature of behaviours and places and have, therefore, explored gender as a lens for understanding the participant’s occupation of certain places.

6.6 The Gendered Nature of Places

The gendered construction of place and activities provides a useful lens to explore the association between the places participants occupy and their identity. Male participants in the study often spoke of their local pub, their rugby club rooms, their cars or boats, and one male, in particular, was often in his garage and workshop planning future projects. Female participants were often in living rooms or kitchens, and spoke of family and their home environment. These findings contributed to my curiosity about the gendered nature of the places participants occupied, as well as the gendered nature of behaviour. Gender typing, the development of gender associated behaviours in society, is discussed by Berk (2004), who suggests that this process begins during preschool development. Berk refers to numerous studies that have demonstrated and explored the association of particular behaviours and activities with particular gendered roles. He suggests that gender socialisation begins at preschool and from this age the gendered nature of roles is reinforced by society. Women are encouraged to act in feminine ways, be sensitive, nurturing, dependent, and obliging; men are encouraged to be strong, capable, masculine, assertive, and aggressive. Males and females tend to occupy different spatial domains, and there are often places within the home that are conceptually regarded as male or female. Women tend to be associated with the domestic sphere and men associated with the public sphere (Rosaldo as cited in Low and Zuniga, 2003).

6.6.1 Jack

Jack was in his early 60s, and he and Betty had tended to perform clearly gendered roles within their home. Betty stayed home and raised their three children, and she did most of

the cooking and housework. Jack worked full time in a physical job and played rugby at the weekend. Jack's daughter Sophie and her husband Paul were visiting him one day when I arrived and I found their conversation enlightening.

Paul and Sophie had decided to change their lifestyle from that modelled by their parents and engage in what they referred to as "role swapping". They had decided that they did not want to have clearly defined gender roles for their children to live by, and had made significant changes in their lives to achieve this goal. One of these changes was that Paul had left his full-time job and now stayed at home, whilst Sophie worked full time. Jack admitted that he found Paul's decision to leave a well-paid job difficult to understand when he had two children and a wife to look after. He said he believed Paul should return to work.

During the conversation, Paul portrayed a sense of respect for Jack in the way he spoke about him. He regarded Jack as a good man, and espoused Jack's manly qualities. In doing so, he reinforced what he considered the gender appropriate nature of Jack's actions:

"Jack has that rugby mentality. In all the years I've known him, regardless of whether he was in pain or not, he would just get up and get on with it. It's sort of a working class, fighting mentality, where you pull up your bootstraps and get on with it."

It appeared that Jack also had clear ideas about his role as breadwinner and provider for his family, typically gendered expectations of a man Jack's age. Jack regarded himself as responsible for the care and comfort of his family and he had passed these beliefs onto his son.

Jack became aware when he was dying that he had not spent a lot of time with his daughters when they were growing up, he said that he did not regard it as appropriate, but he now felt that he missed out on that time with them. Jack said that rather than being this tough man, he would have liked to have been more open with his children about his feelings and tell them that he loved them as they were growing up, and he had not realised this until he became ill. Jack was also known to drink often during his marriage and this had caused a certain amount of friction in his home environment. It was not until Jack was diagnosed with cancer that he stopped drinking and realised that his ideas about the appropriate behaviour for a man had in many ways ostracised him from his family. Jack explained that he tells them he loves them every time he sees them now.

Although Jack's gendered identity was clearly defined throughout his life, he also knew how to cook and look after the house. Jack often talked about housework when I visited him at home. Taking over some of the household chores gave Jack a sense of purpose, and helped maintain a sense of dignity as he felt he could still contribute to the home. Stepping into a different gendered role also gave Jack insight into his wife's life over the years, and he also learnt something about his own behaviour. Jack explained that he originally learnt how to look after a home when he was a child and his mother became seriously ill. He said, *"I either had to learn to cook and feed us kids or starve to death."*

6.6.2 Daniel

Daniel was in his late 50s and his wife Emily in her 30s. Daniel and Emily had clearly defined gender roles within their home. Emily did the housework and most of the cooking

and Daniel dealt with the money and bills. Daniel drove trucks for a living and Emily stayed at home. Emily regarded the housework as her responsibility and preferred Daniel to stay out of her way.

Emily clearly saw the house as her responsibility and she took this responsibility very seriously, just as she took looking after Daniel and feeding him seriously. As Daniel's health deteriorated and he was hospitalised, he and Emily spoke about Daniel going home to die. Emily saw it as her duty, and indeed her right, to meet Daniel's needs at home, and did not want any one else to care for him.

Approximately three months after we met, Daniel bought a car. He then spent most of his time in the car, out and about. Daniel explained that he felt better when he was out driving than he did sitting around the house. Emily did not have a driving licence so Daniel did all the driving. Whilst Emily considered herself in charge of the house, the private sphere, Daniel considered himself in charge when they entered the public sphere. He drove the car, he paid the bills, and he also provided clues about how Emily should behave. The gendered nature of their relationship, their occupation of the home environment, and their views of the places they should occupy all provide information about their gendered roles.

6.6.3 Elisabeth

Elisabeth was in her 70s, and not long after I met her, she told me about her ex-husband. She explained that this had been her second marriage, and she had been married for 15 years. She told me that she had now left her second husband and moved in with her

daughter Penny, who was in her late 30s. Elisabeth and her husband had clearly defined gendered roles and expectations.

Elisabeth's daughter Penny also had clearly defined gender roles in her own relationship. Her partner was a fisherman and often away at sea for extended periods of time. Penny was raising a son and providing care for her mother. She stayed at home and cared for the house as well. Penny said she did the best she could with limited financial resources and two people to care for.

6.6.4 Alice

Alice was in her late 30s and married to Dennis who was about the same age, he was Alice's second husband. Alice and Dennis both worked in traditionally gendered occupations until Alice's diagnosis. Alice's career was in teaching, and Dennis tended to do heavy manual labour. Alice gave up work after her diagnosis and stayed at home. She often baked and cooked meals for Dennis and tried to keep up with the housework. The following provides information about the meaning of these activities for Alice.

As long as Alice could keep doing her housework and caring for her husband, she felt she was still living, so these acts became symbolic of life itself. However, as Alice's health deteriorated, it became very difficult for her to continue doing the household chores and she no longer cooked. Her son Mikey, who was at university, came to live with her, and Dennis left his job and began polytechnic training. Although Dennis and Mikey were often at home during the day, they did not keep up with the day-to-day tasks of running a house.

Once Alice became too ill to tidy the house, it was no longer tidied. Dennis and Mikey spent the bulk of their time watching television or at their computers.

Alice died at home in a bed with no sheets, surrounded by washing that needed to be done. Prior to her death, the house was extremely untidy, but now she was so ill, she could no longer stand, let alone clean or tidy. She had tried asking Dennis and Mikey for help, but she eventually gave up asking. Dennis and Mikey had very limited skills when it came to maintaining their home, but I am unsure whether this was because of the gendered nature of their roles in the past, or as a result of feeling overwhelmed by Alice's impending death. It may have been a little of both.

6.6.5 Helen

Helen was in her late 40s and her husband in his late 50s, their son also lived at home. Helen and Chris had been running their own business for a number of years, and although Helen was now unwell, she was still involved in the business. Helen also did most of the housework and cooking, and her husband helped her. Her son was at university and he worked, but he also helped out when asked. Helen had traditionally done the housework and gardening, and Chris had done the lawns.

As previously mentioned, Helen was often in the kitchen when I arrived and we always sat at the same place at the dining room table. Helen and Chris tended to maintain clearly defined gender roles, and Helen spoke about her concerns for Chris and her son Ben after her death. She told me that she had always done the shopping, bought Chris's clothes, and

kept house. She wanted to teach them some of her family recipes so they could cook them for themselves after she died. Although Helen found it difficult to keep doing even the simplest of tasks at home, she often pushed herself to do so.

Although Chris had not regularly performed household chores prior to Helen's illness, he learnt how to do some things while Helen was still alive and could explain to him how to do them. After Helen's death, Chris carried on her work in the garden, developing new garden areas of his own. He attempted to cook dishes he had never made before, and more than adequately ran the house.

6.6.6 Joan

Joan was in her 70s and her partner Bill in his 60s. Joan was married for many years but her husband Ted had died five years ago. Joan had stayed home and raised their five children and Ted ran a business involving trucks. They had clearly defined gender roles within their relationship. However, after Ted's death Joan decided to run the trucking business and also took up gardening work to make extra money. She continued doing this work until she was diagnosed with cancer two-and-a-half years ago.

Joan managed to develop a multitude of skills that enabled her to perform her and Ted's roles, after his death. She was a resilient woman who believed she could "turn her hand" to most things if she had to. She did not allow the gendered nature of Ted's job to limit her from trying to run his business, even though other men in her age bracket thought her doing so was unusual. Joan also tried to keep up with her own garden, but this became more

difficult as her illness became worse. Joan's partner of the last three years, Bill, tried to help out as best he could.

Gardening was a huge part of Joan's identity, but instead of being able to enjoy her garden, it became symbolic of her illness and the physical limitations she lived with as a result. Although Bill was not able to keep up with the gardening, he was able to help out around the house. Bill had also been married, but had been on his own for a while and learnt how to look after himself and run a home. He was, therefore, fully able to take on the caring role in looking after Joan and maintaining the house.

6.6.7 Billy

Billy was in his mid-40s and Rose in her early 30s, and they had recently met and married. Billy had a passion for cooking and had run a restaurant in his early life. He continued to do quite a lot of cooking at home and he and Rose looked after the house together. They did not have clearly defined gendered roles within the home. They both had some part-time work and were devoted to their spiritual journey. There had been some adjustment to their roles at home since Billy's diagnosis.

6.6.8 Tom

Tom and his partner Michelle were in their late 40s and had three children between them. Tom's wife had died of cancer four years ago, and he had learnt how to care for his sons and the house after her death. His new partner Michelle had also been on her own at times and had raised her son, as well as working and running a home. They now lived together,

with one of Tom's sons and one of Michelle's sons. Although they had both performed a range of tasks throughout their lives, they tended to remain in fairly gender specific roles in their relationship. The gendered nature of Tom's role was highlighted by the following extract. Tom had set himself the goal of being at the Rugby World Cup in France in September 2007, which was ten months from the date of my visit with him:

"I know that's a long way off, but I'm a good staunch Kiwi bloke, I'm not about to roll over and die. It's important to me to fight this, and if I keep a positive attitude and don't give up, I might just make it."

Tom's description of himself as "a good staunch Kiwi bloke", as noted in Chapter Five, was interesting in that he was reflecting the popular image of the New Zealand male as a beer swigging, aggressive, rugby loving man. This was also apparent in the comments Jack's friend Paul made about Jack and his "rugby mentality" and his ability to tough it out, regardless of the pain he was in. Michelle had taken on the role of caring for the house, Tom and the boys, and was trying to hold everything together. Michelle was worried about her son David, and during one of my visits, we discussed ways of involving him more in family events, such as Sunday dinners.

Although gender construction provides a useful lens for the exploration of the participants' identity, the reason why they performed certain roles can not simply be explained by considering gender. Some of the activities participants engaged in held deep symbolic meaning for them and helped them maintain a sense of dignity and worth in a society that often defines a person's worth by their pay packet. In examining their narratives, I considered how people diagnosed with cancer are, in a sense, marginalised in a society that

strives for health, strength, and vitality. For many of the participants, their journeys after diagnosis began with leaving full-time employment and spending time at home, a private space, out of the public eye. Yet participants in the study did not express any feelings of being oppressed; instead, as McDowell (as cited in Fincher, 2007) suggests, as marginalised people, they experience home as a type of life support, a haven from the world. This sentiment is evident in the fact that many of the participants wanted to be at home during their illness, and many of them wanted to die at home (see Chapter Eight). There is one more aspect of “place” that participants related to; this aspect encompassed the places that they talked about or wanted to visit before their died, or the places they had been to and now received joy in recalling and re-experiencing.

6.7 Geographical Fantasy

As the participants’ journeys through illness continued I noticed that some of them spoke more often of travel and places that held meaning for them. In the fieldwork conducted by Rowles (1978) with a group of older people in an inner city neighbourhood, he found that as people’s activities became more constrained there was a greater role played by what he refers to as “geographical fantasy”. Rowles identified two types of geographical fantasy: “reflective geographical fantasy”, which involves reminiscing about places the person has occupied in the past, and “projective geographical fantasy”, which requires vicarious involvement in spatially distant locations. These concepts can be usefully applied to the participants in the current research whose activities were also constrained by their illness.

6.7.1 Jack

Jack was continually frustrated by his physical limitations, and although he desperately tried to keep himself active, he finally had to accept that he was unable to drive to his holiday home or travel to see his daughters in Australia. Whenever one of Jack's children came to visit, his immediate request was that they take him to the holiday home, which they did willingly. In between times, Jack engaged in reflective geographical fantasy, reminiscing about his holiday home and the times that he had spent there with his family over the years. In this way, he was still able to enjoy a place that was precious to him. Jack also engaged in projective geographical fantasy about his holiday home. He had always planned to retire to there with his wife Betty, and he spent a lot of time engaged in vicarious participation in fantasies about their future life together in that location in their "golden years". The other place Jack engaged in with both types of geographical fantasy, reflective and projective, was Australia. Jack and his wife had traditionally travelled to Australia for an annual family reunion, and Jack had thoroughly enjoyed his times there in the past. Jack set himself the goal of flying to Australia at the end of his chemotherapy, and considered how he and Betty would spend time there with their children and grandchildren.

6.7.2 Daniel

During most of his illness, Daniel was still able to drive fairly long distances and he often went on trips with his wife Emily. They would visit Daniel's daughter and family in the North Island or Emily's family on the coast of the South Island. Daniel's goal, in the year following his diagnosis, however, was to go to Rarotonga with Emily. Daniel and Emily would often talk about this trip they were going to make, engaging in projected

geographical fantasy. Neither of them had been to Rarotonga before, and they imagined what it would be like being there. They appeared to gain a sense of happiness from this type of projection. Daniel also engaged in reflective geographical fantasy in relation to his family's Maori land in the North Island. As Daniel's illness progressed, his desire to return once more to this land arose often. He spoke about the land as being quite beautiful, a place that he vicariously experienced as pleasurable in his reminiscing.

6.7.3 Elisabeth

Elisabeth was fairly immobile at the time I met her, and she was very happy living with her daughter in the city. She would, however, often engage in reflective geographical fantasy about the coastal area where she had lived her entire life. She often told me stories about the area and the people who lived there; she seemed to find some joy in these memories. Elisabeth had no plans to go anywhere else, and I never heard her engage in projective geographical fantasy.

6.7.4 Alice

Alice had moved to the city from the lower South Island, where she had been born and where she had lived most of her life. During her illness, she often travelled with her husband Dennis to visit friends in her home town. When I met Alice, she had two projective geographical fantasies; these were to travel to Australia and to fly in a hot air balloon. Alice and Dennis did eventually fly to Australia, but the circumstances were not quite what Alice had hoped for. In Alice's fantasies, the trip involved a romantic interlude for two; in reality, the trip was made because Dennis's mother was seriously ill and thought

to be dying. While there, Alice became very ill from complications with her liver cancer and was admitted to hospital, then transferred back to New Zealand to the public hospital where she had been receiving care. Alice and Dennis received a wedding present of a trip for two in a hot air balloon, a trip they took and enjoyed immensely. After this trip, Alice often engaged in reflective geographical fantasy about the flight, and, in particular, likened her experience of flying to what it must be like to die and float away in peace. Alice also engaged in reflective and projective geographical fantasy about the small town where her grandmother was born, a place Alice loved and where she had lived for a while as a child, a place where her family still returns for holidays. Her reflective fantasies brought her comfort, and her projective fantasies which consisted of being buried in that town, with its genealogical family connections, also seemed to bring her peace.

6.7.5 Helen

Helen and her husband had travelled quite extensively throughout their marriage, and had lived in other countries over the years. As Helen's illness progressed, she often spoke happily of the places she and Chris had travelled to and some of the experiences they had together. This type of reflective geographical fantasy appeared to be a pleasurable experience for Helen. When I first met Helen, she spoke about returning with her mother to their homeland in Europe. For a while, Helen engaged in reflective and projective geographical fantasy about doing so, but decided to make it a reality and began to plan a trip to see her family in Europe. Helen and her mother also planned to meet up with Helen's daughter, who was currently overseas, and spend time with her. Helen and her mother were both diagnosed with cancer within a few years of each other and were aware

that such a trip would be arduous, but were determined to go anyway. After months of planning, Helen and her Mother left for five weeks in Europe in May 2006. Helen returned home, accompanied by her daughter, within two weeks, as she had become very ill with acute liver failure and was dying. Her mother followed her home a few days later, arriving an hour after Helen's death. Prior to leaving for Europe, Chris and Helen had also discussed spending some special time together on the Gold Coast of Australia a month or so after Helen's return. At the time of her death, Helen told me that she regretted that she and Chris would not be able to have time away together as she desperately wanted that time with him before she died. Helen had been engaging in projected geographical fantasy about the time she and Chris would have together on the Gold Coast, and believed that it would have been a very special time for both of them. Rather than feeling consoled by the vicarious experience of being in this place, she felt robbed of the actual experience of being there.

6.7.6 Joan

At the time I met Joan, she was already too weak to travel very far from home. Joan found great solace in vicarious geographical reflections on her previous travels. Joan and I had travelled to many of the same places, so I was able to accompany her on these reminiscent trips and aid her recollection of places. Together, we vicariously revisited a range of places within the United States including the Arizona desert, the Grand Canyon, Yosemite, Bryce Canyon, Monument Valley, Sedona, Las Vegas, San Francisco, and Los Angeles. By the end of our reflective geographical fantasies, Joan would be smiling from ear to ear. She told me that it made her so happy having someone to share memories of those places with.

Joan did not engage in projective geographical fantasies as she believed that there was little point, she knew she would not be travelling again.

6.7.7 Billy

Billy enjoyed regular trips away with his wife in their house-truck at the weekend. He engaged in reflective geographical fantasies about places he had travelled in his life, and discussed memories of his time in Asia when he became very ill with a parasitic infection and returned to New Zealand to be hospitalised. This reflection served as a marker in Billy's journey, a journey which had resulted in worsening health for a number of years, and culminated in his diagnosis of incurable cancer. Projective geographical fantasies that Billy engaged in tended to be related to a shift to live in the place where he and his wife believed they would be happier.

6.7.8 Tom

Tom was quite close to death by the time I met him in late 2006. In the short conversations we had, I became aware of an important reflective geographical fantasy and a projected geographical fantasy. Tom received some pleasure from recalling places he had travelled in his life; however, his primary reflective fantasy was on his last trip to Spain with his partner Michelle. I sensed that his reminiscing was not conducted in order to achieve any pleasure from the memories, but an attempt to understand the sudden decline in his health. It was on this trip a few months earlier that Tom had taken ill and returned to New Zealand barely able to walk. He was then diagnosed with secondary cancer (see Chapter Five, section 5.5.2). Tom did, however, receive great pleasure from his projected geographical

fantasy of travelling to France to watch the Rugby World Cup in 2007. Tom had already bought his tickets, and whenever anyone mentioned his declining health, he merely pointed out that it was his intention to live long enough to go to the World Cup the following year. Unfortunately, Tom died at the end of 2006.

Engaging in geographical fantasies allowed participants to gain access to a greater world than the one they occupied in their physically limited capacities. Projective geographical fantasies appear to have provided goals and hopes and a sense of future for the participants. Helen and Alice were both able to make their projected fantasies into reality, although the outcome for both of them was that they were hospitalised overseas and had to return to New Zealand. Although projective geographical fantasies may have fulfilled a purpose, that of giving participants a sense of hope, the fantasies often turned to regrets as participants realised they were near to death and would not be able to make any of the trips they had fantasised about. Reflective geographical fantasies tended to fulfil two functions. Firstly, they provided a vehicle for participants to ponder their own journey, they marked a point in time that participants considered crucial to their illness process. They often marked a significant point of transition from one state of health to another. Secondly, reflective fantasies provided a vehicle to transport participants to happier times, and happier memories.

In the grounded analysis of the data, the consideration of these recurrent themes in the context of the literature contributed to the realisation of the core significance of “time and

place”. The theme of time and place, provided participants with the impetus to organise constructs for navigating their journeys through chaos towards hope and cohesive endings.

6.8 Cultural Markers: Diagnosis

Moss and Dyck (1999) draw on the metaphors “journey and rite of passage” in describing their participants’ progress from diagnosis to chronic illness. Although the participants in their study did not have cancer, these metaphors are relevant for the research participants in my study, who were diagnosed with cancer and journeyed through chronic illness to the end of life. Moss and Dyck (1999) suggest that bodily markers of ill health, such as sweat and pallor, indicate illness and serve as cultural markers.

Our bodies carry cultural markers that tag us as aged, racialised, sexed, classed, sexualised, disabled or ill. A *cultural marker* is similar to both an artefact and an icon; it is a thing or an object associated with a person’s body that gives meaning to a particular group of people who hold similar overarching values. These cultural markers are for the most part visible and reveal to our cultural reference group an aspect of our identity. (p. 169)

6.8.1 Cultural markers and the invisibility of illness

Moss and Dyck (1999) also discuss how women with Myalgic Encephalomyelitis (ME) have very few cultural markers, rendering their disease invisible. The diagnosis of ME is in itself contestable, which has led to a certain amount of stigma for people with this diagnosis. The diagnosis of cancer is not contested, but unless a patient is receiving treatment or near the end of life, their disease is also invisible. The following situations provide examples of the research participants dealing with the invisibility of cancer.

Alice's way of dealing with the invisibility of her illness was to shock people with this news. In one situation, she told a florist in a shopping mall that she was looking for flowers for her funeral, the florist was quite shocked and told Alice she looked really well and suggested that there may be some hope. Alice just walked away. A couple of months later, Alice decided to undergo another round of chemotherapy and she made the comment:

“People to say me, ‘You don’t look like you’re sick.’ At least this time, they will know won’t they?”

Helen, who was usually a very positive, open and friendly person, was confronted at a vegetable shop for using the disabled car park and was very angry as she informed the woman who challenged her:

“I have breast cancer which has spread to my lungs, my liver and my bones, and I will be lucky to live another year or two, so I think I have every right to park in the disability car park.”

The other issue that Helen mentioned was that, *“Most cancer patients don’t look like they are ill, so people don’t acknowledge their illness.”* This had led to a sense of isolation for Helen.

Moss and Dyck (1999) argue that it is this invisibility which can lead to isolation and marginalisation of people with chronic illness. They state that diagnosis is the most significant cultural marker, and yet this, too, is invisible. The invisibility of these cultural markers makes it difficult for people with some chronic illnesses to identify each other, and to build a collective identity. Moss and Dyck argue that the journey to diagnosis is in itself a rite of passage. This rite of passage was fraught for many of the women in their study,

just as it was for many of my research participants (see Chapter Five). Yet, they argue, that once a diagnosis has been reached, it provides a “script” by which the women in their study were able to “make sense of their experience of illness” (p. 166). Support groups then provided the space in which the women came together to mutually support each other. Through this process, the invisible diagnosis becomes the cultural marker used by the women to identify themselves to each other and receive support (Moss & Dyck, 1999).

6.8.2 Cultural markers: Diagnosis and support groups

One of the participants was involved in a breast cancer support group, and initially found the mutual support from other women experiencing the same illness invaluable. The majority of women in the group had joined it shortly after diagnosis. Being able to meet with other women with the same type of cancer assisted Helen in making decisions about her course of treatment. She decided to undergo breast reconstruction after hearing about other women’s experiences with breast reconstruction. The women in the group provided practical information about surgery and reconstruction that Helen did not find elsewhere. The women also discussed what they believed had contributed to them developing cancer and found that the reasons others gave helped them to make meaning of their diagnosis. The group also provided a space for women to discuss their concerns about treatment and consider treatment options. The group often shared articles with each other that they had found on the internet. Helen showed me several articles and we discussed these during some of my home visits.

A year after my first visit, Helen began to talk about her current feelings of depression and she reflected back on when she had first told her story at the support group. She explained that she felt different from the other women in the group when she first told her story, but as time passed and her cancer progressed, she was able to look back on their stories to help her understand the feelings she was now having. By the time I met Helen, she had been living with cancer for almost three years and no longer attended the group, although she did keep in touch by phone with a few of the woman who were still alive. I asked her why she had stopped going to the group, and she explained that, over time, she went to the group less and less as it became a emotional struggle for her to hold onto hope that she might live when so many of the women in the group died of their disease. Helen explained to me that she had outlived most of the women in the group who also had metastases. I had now been visiting her for over a year, and, at this point, she had lived for more than four years with breast cancer that had metastasized to the liver, lung, and bone, by the time she was diagnosed. She said that women she was in contact with, who were in the group when she began going, were survivors of breast cancer, but did not have her level of metastases at diagnosis. I asked Helen if she was involved in any other groups, and she said that she used to be involved in a craft group, but she no longer attended. She explained that it felt very strange to her that none of the women ever acknowledged her diagnosis or offered her support, and so she stopped going.

6.8.3 Diagnosis and social activities

Diagnosis with cancer appeared to result in a reprioritising of life's activities for the participants. They tended to become more involved in places where their cancer was

acknowledged as an integral part of their identity and where they felt supported in their illness, and less engaged in groups where they felt little support for what they were going through. One month after our first conversation about the craft group, Helen said that she felt uncomfortable about leaving the group without telling them why she had left, and she decided to let them know. This excerpt is from my field-notes:

She called one of the woman and told her why she hadn't been coming to the group. The woman apologised and explained that they just didn't know how to talk about it, so it seemed safer to say nothing.

The following week, Helen received a bunch of flowers and a note from the group apologising and telling her that they did care. Helen seemed to be more at peace with her decision to leave the group after their acknowledgement of her illness. As well as diagnosis providing a cultural marker that bonds women together, this cultural marker can also isolate them from groups they belonged to prior to diagnosis (Moss & Dyck, 1999). This is evident in Helen's experience with her craft group. The women in her group were uncomfortable with Helen's diagnosis of breast cancer, and felt they no longer knew how to respond to her. In response, Helen withdrew from the group because she felt unacknowledged in the aura of silence about her illness. She became more involved in the breast cancer support group, where living with cancer was openly discussed. Helen was the only participant involved in my research who attended a cancer support group after receiving her diagnosis.

Moss and Dyck (1999) state that the women in their study, who were diagnosed with ME, found a sense of belonging with other women who had also been diagnosed. This sense of

belonging also aided the establishment of a collective identity. From Helen's experience, it appears that a similar pattern may occur for women diagnosed with breast cancer. Their diagnosis aligns them with other women who also have the same diagnosis, and assists them in building a collective identity informed by the rhetoric of being cancer "survivors". A contributing factor is that many women are now breast cancer survivors and it is a "visible" cancer if engaging in ordinary activities, such as showering. It may also be because breast cancer strikes at the root of women's bodily identity and, therefore, forces a reconstitution, which is aided by group support. The name of the group Helen attended at the Cancer Society was "New Beginnings"; this name alone speaks of an ethos of living, of a new way of being a woman after the loss or disfigurement of the breast/s, it speaks of beginnings, of surviving, not of death, and not of endings. Yet the reality for Helen was that, over time, many of the women in her group died. The common denominator that had bound Helen to the group, the mutual bond of having breast cancer, was also the reason for her leaving the group, knowing so many women who died of breast cancer.

Although none of the other participants had belonged to support groups, they had also experienced a sense of isolation in social circles they had been involved in prior to their diagnosis. There were multiple instances of withdrawal from social situations for each participant. The meaning behind their withdrawal from these groups was similar to Helen's experience. Once diagnosed with cancer, the invisible cultural marker, the participants felt different from other people who did not have cancer. Their new self-identity as people with incurable cancer appeared to result in a search for meaningful relationships with other people who acknowledged this aspect of their identity. For participants who were not

involved in a support group, this acknowledgement was often sought in particular locations, such as the public hospital oncology department and the cancer ward.

6.8.4 Non-bodily cultural markers

Apart from the cultural marker of diagnosis, which is invisible, there are few other cultural markers that identify people with cancer unless they are having some form of treatment which results in physical changes to their appearance (see section 6.9.7). There are, however, a few cultural markers which have been developed by the hospital in an effort to assist cancer patients to negotiate access to the hospital and the oncology ward.

Throughout the journey from diagnosis to the end of life, there are a variety of cultural markers that identify a person who is having chemotherapy treatment. One such cultural marker that is known to cancer patients having chemotherapy, in the city in which this study was conducted, is the “green card”. The green card is provided by the hospital for patients who are having chemotherapy treatment. It identifies these patients to the staff in the public hospital accident and emergency department (A&E), and indicates that the patient needs to be triaged within 15 minutes of presentation (A. Morgan, personal communication, November 2, 2007). The card also provides after hours emergency phone numbers. As Morgan explained, cancer patients receiving chemotherapy can look reasonably well, even when they have neutropenic septicaemia, and may, therefore, be given a lower priority when presenting at accident and emergency. This was the case in one situation where a woman who presented at accident and emergency died in the waiting

room. The card was developed following this woman's death, and Morgan also began education sessions with accident and emergency staff on neutropenia which are ongoing.

The green card, a color chosen by the printer, is a cultural marker that people who are having chemotherapy treatment know about. Having a green card is like a safety net for patients who may need to access medical help outside of their scheduled appointments. On a couple of occasions, I overheard patients in the oncology suite telling each other about the card and suggesting that others ask for one.

There appeared to be a certain status and a sense of "rights" attached to the holding of a green card. Firstly, it identifies the holder as different from other people when they present at the accident and emergency department. It provides the holder with a sense of unique identity. Secondly, it provides phone numbers to be used after hours. Thirdly, it is regarded as a symbol of the holder's right to be admitted to the oncology ward. For people with cancer, holders of the card are identified as being "in the know", but not in an elitist way, as they let other cancer patients who do not hold a card know about their "right" to have one.

6.8.5 Rights discourse

In Aotearoa New Zealand, the early provision of health services was heavily influenced by the Victorian Poor Laws and, therefore, encompassed moral judgements about deserving and undeserving recipients (Schofield, 2001). Deserving recipients were the old, the young, and the infirm, those who were deemed to be innocent. By the end of World War Two,

hospital services in Aotearoa New Zealand were free and GP visits were heavily subsidised (Schofield, 2001). Citizens came to believe in their “right” to free healthcare provided in a timely manner. In return for free health and welfare services, the citizens worked hard and paid their taxes, believing that if they continued to do so, the government would also continue to honour their side of the bargain. The following quote describes how this code of rights functions:

A right, then, is first and foremost a just expectation, that is, a state of being characterized by ties of mutually expected responsibilities to one another, as individuals and as members of groups and institutions. (Dyck as cited in Redden, 2002, p. 113)

Retrenchment of health services began in Aotearoa New Zealand in the mid-1970s as the welfare budget ballooned. This was followed by a period of managerialism in the 1980s and '90s and the commercialisation of health services. These changes in health provision led to a prioritising of people's illnesses, with the result that the ill were placed on ever-increasing waiting lists. A person requiring elective surgery would be located near the bottom of the list, whereas a person with a terminal illness, such as cancer, would go straight to the top of the list. As one research participant said, *“I knew I must be dying when I was called and told that I had an appointment at the hospital in two days time.”* The process of prioritisation of illness is similar to the original values of deserving encompassed by the Poor Laws. A cancer patient is deemed ill enough to receive immediate treatment and regarded as having the right to appropriate treatment. People with cancer do have specific needs, and cultural markers, such as the green card, reinforce their sense of right to health care, as do other cultural markers used at the hospital. These include: the parking slip oncology patients receive with their appointment so they do not

have to pay for car parking; the parking chits they can get if they do not have a slip and need a car park; and the mobility permit parking card, which allows them to park in designated mobility parking spaces.

6.9 Using Cultural Markers to Negotiate Contested Spaces

Just as the green card provided participants with a sense of moral right and status, but no guarantees, so did the various forms of parking chits given to oncology patients. Participants holding green cards were admitted to other wards, apart from the oncology ward, and some waited for hours in the accident and emergency department. Parking chits, slips, and mobility parking permits do not guarantee that patients will get a car park. These documents do, however, provide the holder with a sense that they have a right to a car park.

6.9.1 The car park as a contested space

The main obstacle that participants encountered when attending the oncology services was the issue of car parking. This obstacle had to be negotiated in order to access treatment and other hospital services. This was a significant obstacle for participants who were weakened by their cancer and often feel unwell.

The car park outside the oncology building is a “public car park” for the use of anyone coming into the hospital for any reason. The car park utilises a “pay and display” system to limit the length of stay. As you walk out of the main door from the oncology department, the car park is on the right. On the left is a specialist wing of the hospital (see Diagram 1). The later addition of this specialist building has altered the landscape, primarily the site

previously known as the oncology car park (see Diagram 2). The driveway into the car park originally came off the main road and into the middle of the car park. To the right, were spaces reserved for oncology patients; to the left, now occupied by the new building, were spaces for public parking. Signs existed on each car parking space.

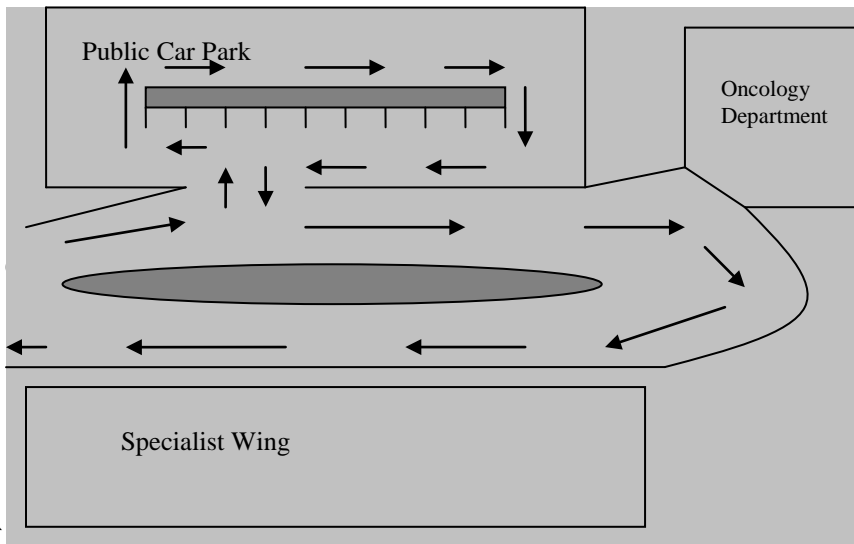


Diagram 1: Altered Landscape. Arrows indicate traffic flow.

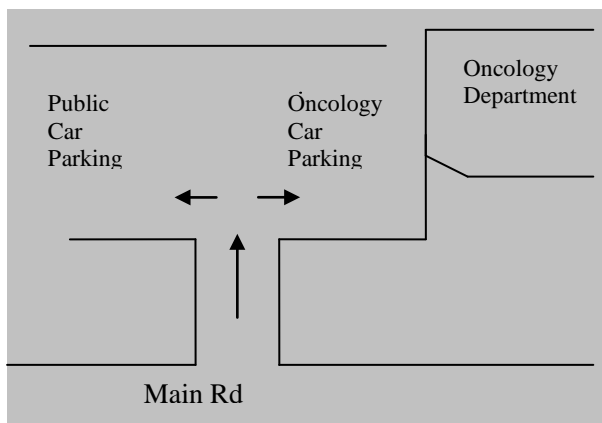


Diagram 2: Original Landscape

When participants first encountered the public car park, they realised that they needed to negotiate this space in order to gain access to health care and treatment. There was a sense that although they had a right to use this space, because they had parking slips, chits, and

mobility parking permits, they would still have to negotiate with others who may also have believed they had a right to park there. There are numerous references to the negotiation of this contested space contained in my field-notes. One of the older participants remembered the original car park landscape and still referred to the public car park as the oncology car park. The historical legacy often led oncology patients to assume a certain right to the public car park area. This resulted in participants and other oncology patients believing that their rights were being violated when people who were not going into the oncology department took the parking space they were waiting for.

I noticed that there was a definite car parking culture that had developed in this car park. There seemed to be an unwritten rule that cars queue behind each other and in turn take a car park. Now and then a driver who did not understand the culture of the car park would come in the entrance and drive past all the waiting cars and either wait further up the car park, thereby “queue jumping”, or drive out again. If the “queue jumper” took a car park, the watching drivers would reprimand them for violating the cultural norms of the car park and explain in detail the correct way of queuing.

Street parking was available around the perimeter of the hospital but this was limited to 120 minutes. It was not unusual for oncology appointments to take longer than expected and chemotherapy treatment can take from 1-6 hours depending on a number of factors. This situation caused conflict and tension between family members also attending oncology appointments as they would have to leave to top up the parking meter or risk a parking violation at a time when they were trying to deal with an emotionally-loaded

situation. The other option was to park in the main hospital car park building. Using the car park building is more expensive than street parking; however, cost was not the main barrier to using the car park building. The distance was also a barrier for some participants who could not walk from the car park building to the oncology waiting room, and there were no wheelchairs available at the car park building.

Mobility parking permits were quite useful for accessing some hospital car parks. Although all the participants were entitled to have a permit, not all of them did because of the difficulty in obtaining one. This required them to have forms completed by their doctor, and then to take these forms to another organisation to apply for the permit which then had to be paid for. On one hand, these permits saved time and improved access to space. On the other hand, holding such documents also had implications about the diminishing health and ability of the holder and identified them as people with an illness. While parking was an issue for the ill participants, it was also an issue for family members visiting the ill participants in hospital. If a terminally-ill participant was admitted for a period of time, the family member visiting most often could make an appointment with the parking warden and apply for a parking ticket that would cover the cost of regular parking.

The participants were people who were experiencing an illness which they knew would result in their death. They were facing the biggest crisis of their lives, their death, and yet they must continually deal with the mundane issue of getting a car park. The reality was that they still needed to get a car park before they could put the permits and chits on their dashboard to declare their right to occupy the space. Participants were dealing with this

ongoing issue whilst also dealing with their feelings of ambiguity about having to be at the hospital in the first place. Although participants wanted to be on time for their oncology appointments, they also wished they did not to have to be there at all.

Dealing with the added stress caused by parking issues was often overwhelming for participants, who sometimes struggled to get out of bed in the morning. The cost of car parking was also an issue when financial issues were being experienced by all the participants, due to loss of income as well as additional medical costs. Penny raised the issue of time being wasted in having to leave home early to get a car park in time for the appointment. Her comment made me aware that time is often counted in minutes, hours, and days, when time and energy resources are limited.

The cultural markers explored so far, the green card, parking chits and slips, and mobility parking permits, are all provided by the public hospital. Moving away from the car parking issues as cultural markers, there is another cultural marker I would like to discuss; this marker is related to the physical body.

6.10 Bodily Cultural Markers

A common physical cultural marker that is seen in people with cancer who are having chemotherapy treatment is hair loss. Hair loss is a cultural marker that is understood by the public, as it indicates that the person without hair has cancer. The following extracts examine how two participants felt about being identified by these cultural markers in

public places. I also examine how two participants' views changed over the course of a year.

Helen says she doesn't like people who don't know her discovering that she has cancer, so she wears a wig.

One year later:

Helen said it would be too hot to wear her wig. We talked about headscarves and hats, but Helen said that she didn't mind if people "looked at her funny".

Alice is beginning chemotherapy and she has decided to shave her head this time as it was quite painful letting her hair fall out last time. Alice says to me, "At least people will know I am sick now." She shaved her head before beginning chemotherapy, and she never wore a wig.

Initially, Helen did not want people to know that she had cancer. A year later, Helen said she did not mind if people "looked at her funny". Alice struggled with the lack of acknowledgement of her illness when I first met her. She saw hair loss as a mechanism to let people know that she was sick. This would bring a measure of understanding that she did not get when her disease was invisible. One of the male participants also experienced hair loss. Daniel loved his long hair and was very proud of it. He was not worried about what other people would think about his hair falling out, or if they realised that he is ill, he just did not want to lose his hair because he liked it. I had an opportunity to attend the Cancer Society's "Look Good Feel Better" workshop with Alice; this experience led to a deeper exploration and reflection on the invisibility/visibility of cancer patients' illness, and the use of wigs and make-up to mask hair loss.

The woman running the workshop welcomes everyone, and explains that she would like the women participating in the workshop to remove their wigs, scarves, and hats, and that they will be putting them back on at the end of

the workshop after their make-up is done. I look around the room and realise that I could be sitting in any group of woman at this point. There is an inner circle of women around the table and an outer circle of woman who have come with the workshop participants. Apart from Alice and one other woman in wheelchairs, there are no obvious signs that any of the women in the room are unwell. Then they begin to remove their wigs and the room is virtually transformed. There is now an inner circle of approximately 20 women, and half to three-quarters of them have little or no hair, it is quite a startling experience.

Attending this workshop was a poignant experience in the development of my understanding of the invisibility of cancer. I had often visited participants at home who had no hair and no wig on, and was never surprised to see them this way. However, to watch a group of women become transformed in front of me was a new experience, an experience that I would not encounter in any other situation. Hair loss as a cultural marker of cancer is understood by the wider society. This cultural marker is invisible when cancer patients wear a wig, but often noticed when cancer patients wear a hat or bandana. The bandana has also become a cultural marker of cancer and has been used in fund-raising events in Aotearoa New Zealand.

The cultural markers discussed so far are fairly general in nature and known to a majority of oncology patients. There are, however, other cultural markers known to subgroups within the main group of cancer patients. Examples of subgroups could be people with different types of cancer, people at different stages in their illness, or people having particular treatment regimes. Patients with renal or bowel cancer often notice other patients who have colostomy and nephrostomy bags. Patients using walking frames, wheelchairs, or other aids often understand that their health is deteriorating as they are becoming weaker and need more assistance. This understanding is reflected upon when they see other cancer

patients using the same supports. Patients having chemotherapy often notice other patients who have Hickman and PICC-Lines, which are used to deliver chemotherapy into the body when patients' veins are difficult to find. Space inside and outside the body is taken up by the contingencies of cancer and constantly reminds those "in the know" of the temporality of life.

6.11 Conclusion

My journey with the participants began in their homes and continued through their engagement with health carers and providers. My journey with the eight terminally-ill participants ended at the time of their death. Through joining the participants at the beginning of their rite of passage, their transition from "able-bodied members of society" to "a person living with cancer", I was able to explore the meaning of the places participants occupied or had occupied on their journey through life. In accordance with ethnographic research and grounded analysis, and attempting to understand the meanings of the places participants occupy, I was often what Rowles (1978) referred to as "fumbling for meaning". I engaged in a review of literature from a number of sources. The concepts and frameworks discovered in this process provided the structure for the analysis of the data.

Drawing on the work of Richardson (2003), I developed a written description of the context, appearance, and contents of the eight participants' homes. Although the basic appearance of the participants' homes provided some insight into the participants' culture, it told me only a little about the personal meanings they attached to "home". Rowles's (1978) finding that the older people he studied lived within a changing relationship with

their environment due to physical limitations assisted my understanding of the changing nature of my participants' relationships with their home environments. I explored the point in participants' journeys where they made a transition from one social category to another, a time that Kenworthy Teather (1999) refers to as a rite of passage. This rite of passage often resulted in an immediate reduction in the number of social spaces the participants occupied. This was later offset by their engagement with other places, places that were focused on the participants' physical well-being. Two of these places are analysed in the following chapter, Chapter Seven: the chemotherapy suite and the oncology ward.

Through developing an open, reciprocal relationship with participants, we, as researchers, can develop a special sensitivity to their geographical experiences of place (Rowles, 1978). By mutually exploring the meaning of place, the researcher becomes, in a sense, "the other", and it is through becoming the other, that participants' experiences become the researcher's experiences. In order to understand as much as possible about the connections between place and identity, I explored the data concerning participants' occupation of their home environment and considered the gendered nature of the places they occupied. I found that although the majority of participants performed what Berk (2004) refers to as gender appropriate roles within their relationships, there was often an adjustment to these roles after diagnosis. There was also a change in the existential meanings attached to the performing of certain roles.

Geographical fantasies appeared to provide participants with ample material for the consideration of their life's journey. For some participants, reflective fantasies were

conducted in search of an explanation of their current diagnosis. For others, it served to remove them from the limitations imposed by their physical decline. Projective geographical fantasies appeared to serve quite a different purpose; they seemed to contain hope for a future time. Some participants turned their projective fantasies into reality, but, in so doing, were given clear reminders of the physical limitations imposed by their illness. Some participants accepted the inevitability of their physical decline and held on to their reflective fantasies, never developing projective fantasies.

The participants began to engage with the new cultural realm of the hospital and health systems. This cultural realm is comprised of support groups, a variety of hospital departments, hospital car parks, and the Cancer Society. In these locations, the participants developed a new identity, that of people with cancer. I also explored the invisible and visible cultural markers that identify people with cancer.

Visible cultural markers which were imbued with meaning for cancer patients, included non-physical cultural markers, such as the green card, car parking chits and slips. These parking documents were place specific, relating only to the hospital setting. Mobility parking permits were used in many different places to access a particular parking space. Participants' identity as cancer patients was reinforced by the holding of these parking documents which improved their access to space and saved time. Because of the shortage of car parks and the geographical history of the car parking landscape, the car park remained a contested space which participants needed to negotiate while dealing with their ambivalence about having to be there at all.

One of the bodily cultural markers explored in this chapter, hair loss, is sometimes a visible indicator of cancer and it is sometimes masked. It is a physical cultural marker understood by wider society as indicating that a person has cancer. How participants felt about this cultural marker, identifying them as people living with cancer, changed over time. How they felt about being identified was also context dependent. In the Cancer Society's "Look Good Feel Good" workshop, women with cancer were sharing the space and experience with other people with cancer; therefore, having no hair contributed to a sense of belonging. In other situations and places, these cultural markers identified them as "different from". The cultural markers discussed in this chapter were encountered early on in the participants' journeys. This is not an exhaustive list, but an exploration of some of the most obvious cultural markers that participants encountered. There are many other cultural markers encountered by people with cancer in the course of their journeys.

In this chapter, the participants began to develop context dependent, cultural identities as cancer patients. The following chapter, Chapter Seven, explores their engagement with palliative care services. As time and space have continued to emerge as core categories, Chapter Seven provides an in-depth analysis of two places within the health system where participants spent a great amount of time: the oncology ward and the chemotherapy suite. Moved forward by time and increasing physical deterioration, participants and their families entered the final part of their journeys, the last few weeks or days of life. Chapter Eight, therefore, includes a discussion of the one final place of importance to participants, a place that was often, but not always, discussed by participants and their families: a place to die.

Chapter Seven

Embodied Spaces

Places are not inert containers. They are politicized, culturally relative, historically specific, local and multiple constructions.
(Rodman, 2003, p. 205)

7.1 Introduction

The diagnosis of incurable cancer, explored in Chapter Five, led participants to reconsider their lives and identities. Chapter Six explored how participants engaged in a rite of passage during which their identity was irreversibly altered from employed able-bodied person, to unemployed or part-time employed, ill person with cancer. The connections between time and space/place, identity, and culture, were also explored in light of the participants' home environments and negotiations of public space and perceptions. The early process of engagement with palliative care systems added another dimension to the participants' new identity through the process of enculturation. As participants' journeys brought them in contact with health services they began to understand the cultural markers relative to cancer and the places that people with cancer occupy. In this chapter, I further explore the meanings constructed in and around the places occupied by participants as cancer patients. Attention will be given to the reciprocal relationship between behaviour and place. This will be done by considering the embodied meaning of two places within the health system participants occupied during the course of the fieldwork: the oncology department and the chemotherapy suite.

As discussed in Chapter Four (see section 4.6.4), ethnographic data collection methods are compatible with grounded theory methods of analysis. This is because ethnography is a natural method of exploration and grounded theory is most effective when used to analyse data collected in natural settings. From the process of comparing the classification codes using the computer software programme NVivo 7, I became aware of the commonalities of these codes in that they were all related to events that occurred in particular places and at particular times. With further comparison, I became aware that the contradictions were also time and place specific. Through this process emerged the primary theoretical concepts relating to behaviour that was in, and of, a variety of different places. Further grounded analysis of this context dependent behaviour led to the development of “time and place” as one of the core categories. Having established what the core categories were, I returned to the literature to find an effective method of analytically presenting the findings. Such a framework was provided by ethnographer Miles Richardson (2003). I have outlined his framework in section 7.3.

7.2 Ethnography and Place

Ethnography is conducted in particular places, locations and settings, therefore, attention is given to the context in which data collection occurs. In the early stages of the grounded analysis, it comes as no surprise that “place” emerged repeatedly as a node in the data. Kottak (2002) states: “In a given society or community, the ethnographer moves from setting to setting, place to place, and subject to subject to discover the totality and interconnectedness of social life” (p. 34). The primary places I occupied with the participants in the course of my fieldwork were their homes, hospital wards, the oncology

department, and the chemotherapy suite. Two of these places, the chemotherapy suite and the oncology ward, will be explored by examining extracts from the observational data recorded in field-notes. Kottak (2002) aptly describes this ethnographic process in the following way:

By participating in the community we are studying, we begin to understand the meaning of activities or places. First there is a naming phase, where we constantly ask the names of items. We meet key cultural consultants who are experts on their environment. We gather intimate and cultural personal histories from people who get involved in our research. The lives people in these places live are referred to by Geertz as 'meaningful texts'. And as ethnographers we need to learn how to interpret them. (p. 34)

As Kottak (2002) suggests, people are cultural beings, places have their own cultural identities and cultural consultants, yet culture remains an elusive quality, that is difficult to define. Ethnography allows us to examine culture by paying attention to the multiple voices heard and recorded during fieldwork, and to consider the multiple locations in which these voices are heard. Rodman (2003) suggests that by doing this we can "look 'through' these places, explore their links with others, consider why they are constructed as they are, see how places represent people, and begin to understand how people embody places" (p. 218).

The notion of embodied spaces is used to describe the conjunction of physical being and place and the interaction of the two. As we move through the world in our physical, biological bodies, we encounter spatial environments in which we create lived experiences. When these experiences are reflected upon or discussed by the person who experienced them, the place is also recalled. Experiences happen in place, to the person who occupies the space; this is embodiment (Low & Lawrence-Zuniga, 2003).

7.3 Place and Culture

To highlight the often obscure and subtle characteristics of culture, I have utilised, as noted above, the concepts and ideas of ethnographer Miles Richardson (2003). Richardson presents his ethnographic data using three components: “the preliminary definition of the material setting, the interaction taking place in the setting, and the image that completes the definition” (p. 77). To understand the preliminary definition of the material setting, Richardson makes the context, appearance, content, and image of two different settings explicit. He then contrasts the components of the two settings to draw out the critical differences inherent in them. The two settings I have selected, the chemotherapy suite and the oncology ward, are both located in the main public hospital.

Next Richardson considers the interactions that occur within each setting by conducting a systematic analysis of the interactions, considering people’s level of engagement, their role as participants or observers, whether the interactions were intense or serene, and whether the people were “onstage or offstage” (Goffman as cited in Richardson, 2003). Conducting a systematic analysis makes the behaviour in each setting explicit and, therefore, available for critical analysis. The critical analysis highlights the differences in people’s behaviour in the two settings.

Once the setting and the interactions have been considered separately, the ethnographer “brings them together for a statement on the overall meaning of the two places” (Richardson, 2003, p. 85). To complete the analysis, Richardson provides a final contrast of the two overall statements. He explains that the ethnographic text is the meaningful result

of the setting and the interactions “the objectified result”. Richardson’s basic argument is that by incorporating the material setting into the situation we move from simply being-there to being-in-the-world. It is through actions in these places that culture forms or “becomes”.

7.3.1 Chemotherapy suite context, appearance, contents, and theme

The chemotherapy suite in this study is located within the public hospital oncology department. The oncology department is on the outer edge of the wider hospital and can be accessed via the main hospital or a lower ground entrance. The chemotherapy suite has one external wall with windows, from which you can see the public car park and beyond to the botanic gardens. The remaining walls are all part of the internal structure of the oncology department.

The main door to the chemotherapy suite opens into a large, bright room approximately eight metres square. There is a light, open feeling to the suite which has been achieved by the use of pale pastel shades on the walls, and building materials that have maximised the natural light from the windows. The layout of the chemotherapy suite is shown in Diagram 3.

The external corner of the nurses’ office contains large windows placed at the junction of the two walls forming a large corner window (indicated by broken lines). This corner window allows the light from the external windows to flow through the office into the rest of the oncology suite. It also adds to an open, cohesive feeling on entering the suite and the

office is immediately visible. Staff in the office can observe patients receiving chemotherapy and are, therefore, able to respond when a patient needs them.

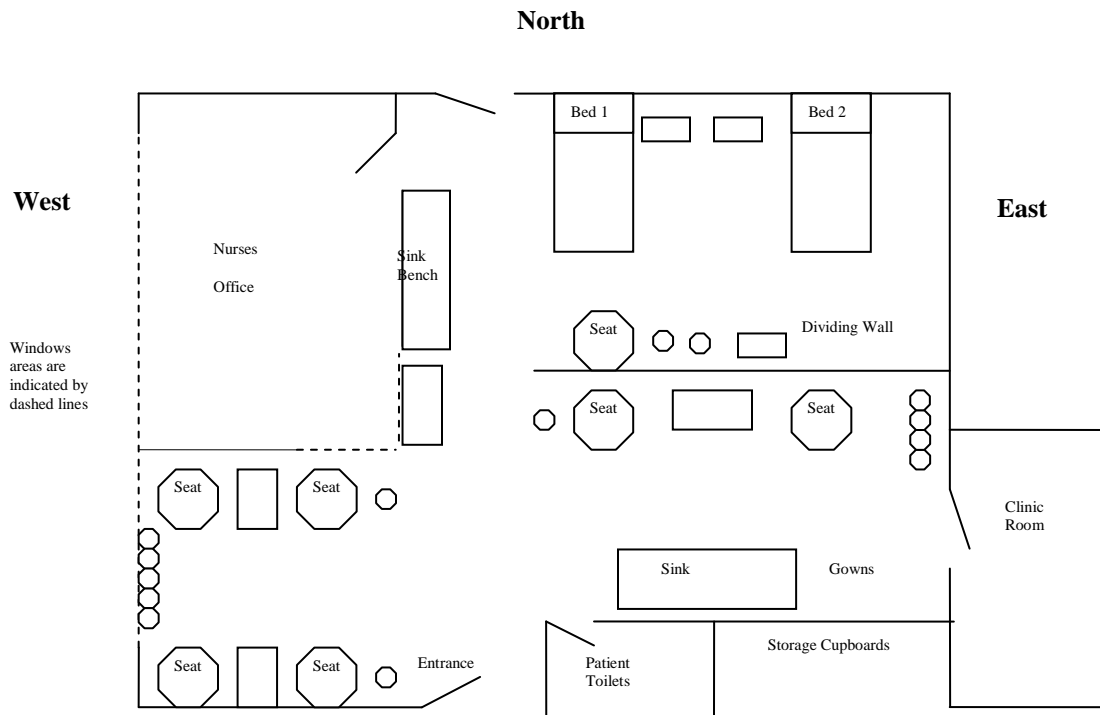


Diagram 3: Oncology Department Chemotherapy Suite

The chemotherapy suite is often a very busy place, especially when all patient spaces are occupied. The activity of the suite can also be attributed to the design, as it is an open room which connects multiple spaces. At certain times of the day, the chemotherapy suite is a very busy, active place, and at other times, it is devoid of activity and people. It is a place often attended by people at the beginning of their cancer journey, when they engage in initial chemotherapy treatment. For many participants it was also the place they returned to at different times in their cancer journey. When people first come to the chemotherapy suite for treatment, they tend to be quieter and follow the cues provided by other people about

behaviour that is appropriate in that environment. They wait to be given a seat, and they wait to be told what to do and when. After a period of time, people become enculturated to the chemotherapy suite and walk in the door, wave “hello” to the nurses, choose their own seat, and set themselves up for the start of their treatment.

Thematically, the oncology suite is a therapeutic clinical space that is full of people and activity during business hours, and generally closed in the evenings and weekends. It is a treatment space, where recipients of chemotherapy hope that the treatment will either cure their cancer, or give them longer to live. It is a place that many patients receiving chemotherapy get to know well, as they spend significant amounts of time there. In order to understand participants’ experiences “of” and “in” this place, and at their invitation, I attended chemotherapy treatments with three of the participants. For the most part, I drove the participants to and from the hospital for their treatment.

Daniel attended the chemotherapy suite for three consecutive days, every three weeks, for four months. He would often be in the suite for up to five hours at a time. Helen attended one day, every three weeks, for six months, and was usually there for four to five hours at a time. Alice attended for two days, every month, for six months, and was there for five or more hours. The oncology team was cheerful, friendly, welcoming, and generally became familiar with patients during their treatment. The team at the chemotherapy suite was fairly stable during the fieldwork, and the nurses became familiar to patients who attended oncology regularly. There were often up to six nurses in the chemotherapy suite. The team tended to work in the oncology clinic, the chemotherapy suite, and, sometimes, in the

oncology ward. The oncology nursing team was known by patients on a first name basis, and vice versa. In the office there were often cards, baking, and boxes of chocolates that had been given to the team by patients who had completed chemotherapy.

7.3.2 Oncology ward context, appearance, contents, and theme

The main oncology ward is located on the third floor of the hospital building and looks out over a river and the gardens on the other side. There are often people passing on the river in canoes, kayaks and punts. On the hospital side of the river, there is a wide, grass area with seats, where patients tend to go to sit outside in the sun, or to have a cigarette. The oncology ward can also be accessed via the main hospital entrance or the lower ground entrance. The ward is located on the north side of the hospital, whereas, the oncology department is located on the south-west side. Consequently, a long walk is involved for people who need to move between the two places.

The layout of the oncology ward is shown in Diagram 4. There are two sets of double doors that lead to the ward. The first set of doors, accessed from the lifts or stairs to the ward, are usually closed (entrance 1) with a sign which reads “Please use other entrance” (entrance 2). Entrance 1 provides access to eight single-bed rooms, often used for very sick or dying individuals, so any foot traffic is diverted to the second entrance. The second entrance doors remain open from early morning until rest period at 1pm. They are then closed until 3pm. A sign is placed outside the door informing visitors that visiting continues after 3pm.

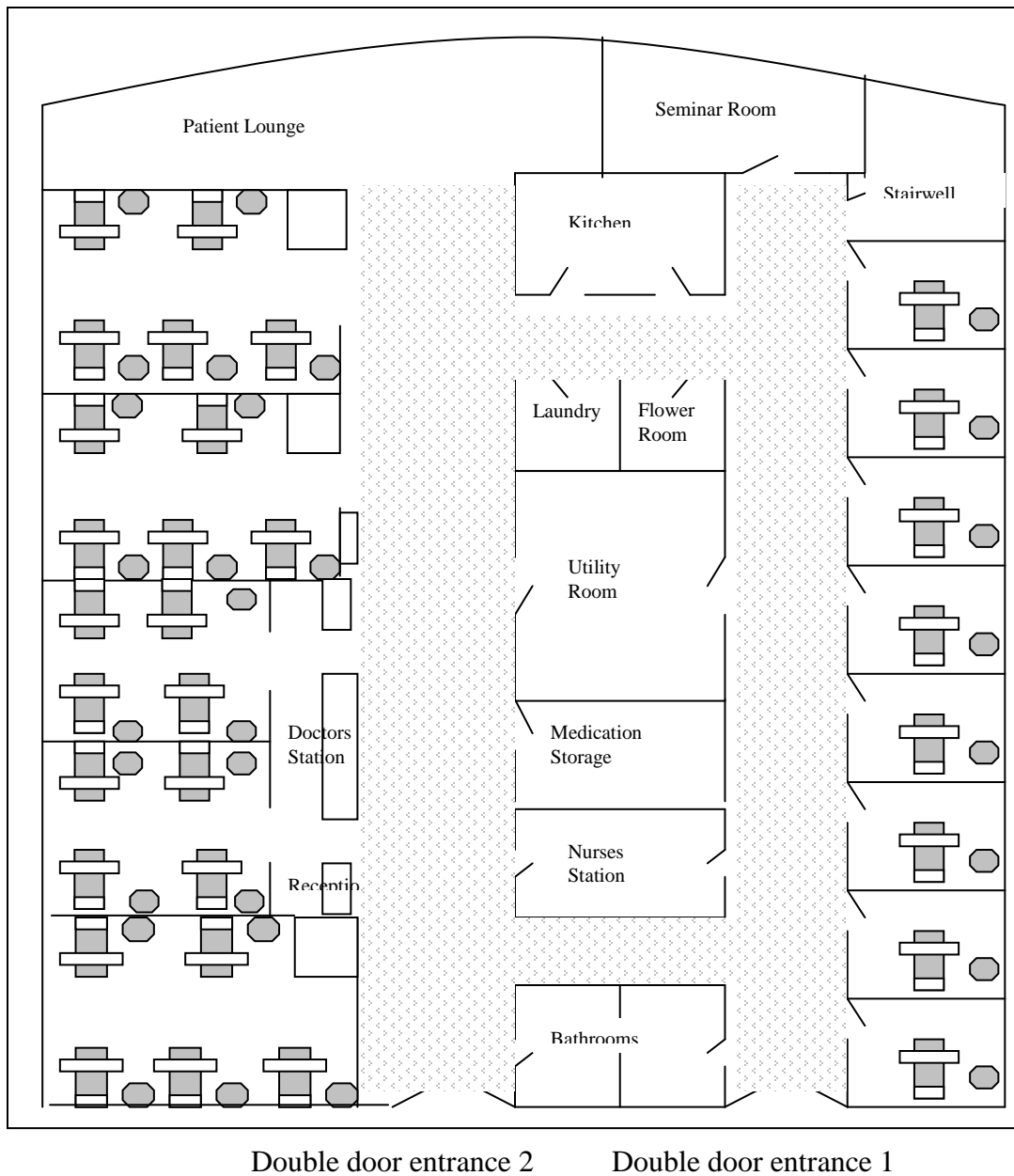


Diagram 4: Oncology Ward

In a similar manner to the chemotherapy suite, the the oncology ward is painted in pale pastel shades, and there are cream curtains around the beds. There is a floral pattern of muted tones on the curtains that cover the windows. The main corridor into the ward is approximately two metres wide and is carpeted. In total, the oncology ward has 31 patient beds. On this side of the ward, along the main corridor, there are five rooms of four to five

beds. At the end of the hallway, there is a patient lounge which is light and very sunny on fine days. It has a rounded back wall which contains large opening windows.

The second corridor on the other side of the ward, from which the eight single-bed rooms can be accessed, is also approximately two metres wide. It is completed in the same décor as the other side of the ward. Whereas there is a lounge at the end of the main corridor, there is a seminar room and a staircase at the end of this corridor.

Each room is sparsely furnished: there are beds and bedside cabinets, and a few chairs for visitors. On the walls in each room are one or two framed pictures, usually country scenes, and the usual medical equipment—ports for oxygen, lights, emergency buttons, and a name plate. There are few flowers in this ward as patients are admitted regularly in comparison to other wards where patients may be admitted on an irregular basis, and after many admissions people stop bringing flowers. There are also wards within the hospital where flowers are not allowed but the oncology ward is not one of these.

The most inviting space within the ward is the patients' lounge, located at the end of the main corridor. The lounge contains dusky pink couches and seats, and two brown-toned recliner chairs and a small television. There is also a bookcase full of books and reading material on the wall next to the television. This room is very light, due to the large windows on the half-round back wall. On a summer's day, it is a beautiful room to sit in. When the windows, which slide up by about half a metre, are opened, the sounds of people enjoying life in the gardens and river below filter into the room. One other area that

contains colour in this ward is a photo wall in the small hallway near the front of the ward, next to the nurses' station. There are photos of patients and oncology staff, and people often stop for a while to look at the photos.

The theme of the ward is clinical in nature, but it is a quiet place for very ill cancer patients. Patients stay in the ward because of health complications, hoping to get better and be discharged home. There are patients who are admitted to the ward because of deteriorating health, and there are patients who eventually die there. Thematically, it is a place of quiet rest, but it is also a gathering place, a place where families congregate when a loved one is dying. It is not uncommon to see families gathered in the side hall outside one of the single rooms, or sitting in the patients' lounge. Because of the different nature of both sides of the ward, each side has a unique culture. In the main corridor, people speak in normal, but subdued tones of voice. In the corridor where the single rooms are located, people speak in hushed voices, mindful of other very ill patients. Often doors are shut on this side of the ward; whereas there are no doors to the communal rooms on the other side of the ward. The lounge at the end of the main corridor is open, there are no doors separating it from the corridor. By contrast, the seminar room at the end of the second corridor is completely closed off and has a locked door. There is more activity in the main corridor, particularly when the doctors and nurses congregate around the central desk to review patient files. The receptionist receives queries from visitors and patients, and there are phones ringing. Once the doctors have left the ward, there are fewer staff members available on the ward, and there may only be three or four nurses on the ward at a time. In the second corridor, there

are no places for staff to congregate, no desks, and no telephones. It is a space that visitors, doctors, and nurses, pass through to enter or leave one of the side rooms.

7.4 Critical Contrast of the Two Material Settings

Patients in the chemotherapy suite, who are often in the recliner chairs, are dressed in clothes and shoes, are quite lively, and often look quite well. They are generally talkative, and often look as if they have come straight from work or some other activity. There is a sense of connection to living. There is a sense that people are “onstage” in the chemotherapy suite and “off-stage” in the ward (Richardson, 2003). Patients in the ward are usually in pyjamas, nightgowns, dressing-gowns, and slippers. The majority of patients in the chemotherapy suite sit in chairs, fairly close together, which leads to conversations and connections being made. In the ward, there is some conversation but generally less interaction than in the chemotherapy suite, as patients are divided into separate bed spaces. The ward is generally a quiet space, in comparison to the chemotherapy suite. People come to the ward because they are too ill to be at home, or because they are dying.

7.5 Interactions Taking Place in the Settings

People preliminarily interpret the material locations they encounter and develop appropriate “in-place” behaviour (Richardson, 2003). This situational behaviour can be either “in” the place or “of” the place. The ways in which different people respond to a particular material location will vary and, therefore, these can be difficult to quantify and record. There is, however, meaning attached to the behaviours that occur in certain

locations, behaviours that are “in-place” rather than “out-of-place”. Often one defines the other, as Richardson explains:

Interaction that people interpret as incorporating the preliminary definition transforms a purely ‘crude,’ ethological ‘conversation of gestures’ (Strauss 1964:154-162) to meaningful, symbolic interaction. The movement is from simply being there to being-in-the-world. Conversely, interaction that people interpret as challenging the preliminary definition also achieves meaning but the meaning it achieves is that of being out of place, of being-out-of-the-world now taking shape. (p. 80)

To illustrate Richardson’s point, I have provided one example of in-place behaviour and one example of out-of-place behaviour; these are extracts from observations recorded in my field-notes:

The man in the bed opposite Jack is called Ernie. He has been here for over a week now, so we say “Hello” to each other when I arrive. There is a new man in the bed next to Jack. Jack and I say “Hi”, and he tells me in a whisper that the new man in the bed next to him is dying, and he only came in last night. The man’s adult children, two men and a woman, are standing around his bed looking very anxious. The woman, his daughter, is pregnant and looks very worried, she is attempting to read a book but continually glances at her father anxiously. Ernie’s wife is sitting next to him and they talk quietly. One of the nurses comes into the room and pulls the curtain around the dying man’s bed-space. The nurse talks to the family quietly and calmly, and makes suggestions about what can help. He suggests that they bring some massage oil in as even though their father is not conscious, this will be soothing for him, and it lets him know that they are there with him.

This is a fairly common situation in the ward, where there are quiet voices and a sense of reverence around the beds of the very ill. The family’s behaviour is meaningful in this context, which, in Richardson’s terms, transforms their behaviour from being-there to being-in-the-world. The family members receive positive praise from other health

professionals who enter the room. Their behaviour is in-place, regarded as appropriate to the setting. The extract below provides a description of out-of-place behaviour:

Jack's uncle, Harry, came into the ward and went to Jack's door (one of the single rooms) but the nurses were in with Jack. They told Harry they would be finished in a moment. He said, "Okay", and came to stand with me and other family members in the hallway. His cell phone went off and he answered it. The receptionist told him off in no uncertain words. She told him that he was not allowed his phone on when he was on the ward. He said, "Sorry", and walked back out of the ward to continue his phone conversation.

People who engage in out-of-place behaviour, as above, are quickly reprimanded by people who Kottak (2002) refers to as key cultural consultants. In this way, the offending person alters their behaviour to fit the environment and learns the cultural norms of the particular place.

Richardson (2003) suggests that to understand behaviour that occurs "in" and "of" different places, it is necessary to compare a sample of interactions in one setting with interactions in another setting. I have undertaken such a comparison in relation to interactions in the oncology ward and the chemotherapy suite. I have contrasted a range of field-note extracts from both settings to highlight the connection between the material settings and the emerging interactions. Behaviour that occurs in certain places challenges or incorporates peoples' preliminary understanding of the environment. Emerging from this process is a definition of the culture of the setting and the meaning of the setting for participants.

7.5.1 Interactions in the oncology ward

As explained in Chapter Four, I used the computer software programme NVivo 7 for data searches and management and to aid me in my grounded analysis. Using its search functions, I was able to establish that there are a total of 182 references to the oncology ward in my field-notes. Out of these references, I established 108 codes relating to interactions in the ward. The following interactions have been chosen as they represent a cross section of the type of interactions that are most common in the ward:

Interaction 1: Visit to Alice, Oncology Ward—Five-bed room

I am visiting Alice in the oncology ward. She is sharing the room with three other women whose ages range from 65 to late 90s. The oldest woman in the room, Edith, who has dementia, thinks that every time there is a beep, it is the phone for her. Alice's pump is getting low so it keeps beeping. This creates havoc in the room as Edith keeps asking one of the other ladies in the room if that is the telephone. The lady is getting annoyed with Edith and complains about her and the staff to her visitor. Alice explains that the woman is always complaining, and Alice would love to move to another room to get away from her.

Interaction 2: Visit to Elisabeth, Oncology Ward—Five-bed room

I am visiting Elisabeth in the oncology ward. She is in the last of the five-bed rooms at the end of the ward. She is sharing the room with four other women whose ages range from approximately 50 to 70. Elisabeth looks very cosy and comfortable, and the nurse is helping her to get ready for bed. The nurse does not speak to Elisabeth as she is helping her. I ask if I am in the way and she replies, "No". That is the only word she says, and then she leaves. Other nurses come into the room to help the other ladies, and the nurses are friendly and chatty. Although it is visiting hours, none of the other ladies have visitors present.

Interaction 3: Visiting Daniel, Oncology Ward—Four-bed room

I am visiting Daniel and he is in the second of the four-bed rooms in the oncology ward. I ask him how his weekend had been and he said he had gotten really bored. His wife Emily tells him to tell me what he did. She looked at me, and I asked if he had been sick and she said, "No, he went out." Then Daniel said he didn't want his sister Sheena and that to know. I said that was fair enough and that I wouldn't say anything. Then Emily said he called a taxi, he went downstairs and met it outside and went to the pub. He said he walked into the pub in his pyjamas and had a gamble

on the pokie (slot) machines. He said that people looked at him a bit funny but he didn't care. He said he left his wheelchair downstairs and was only gone an hour. He said he didn't want anyone to know, but he was bored.

The following extracts are also from my observations of interactions in the oncology ward, but they are somewhat different from the previous notes, as they are about participants' transitions to the other side of the ward, or interactions in and around the single rooms. These are provided to illustrate the different cultures of the two sides of the ward. The interactions in the four- to five-bed rooms tended to be among the patients, staff, and few visitors. The interactions on the other side of the ward, in the single rooms, tended to involve more visitors and family members, fewer staff members, and no other patients. The interactions tended to be more emotionally charged, as the participants on this side of the ward were often approaching death.

Interaction 5: Visiting Jack, Oncology Ward—Five-bed room and side room

I arrived to visit Jack this morning and his nurse, Rebecca, said that Jack was a bit worse today and that she had alerted the family that it would be a good idea for all of them to come in When the family arrived, Jack's daughter Sarah said, "I'm really confused, I can't see what has changed since yesterday, so why did Rebecca call me and tell me to rally the troops?". . . She asks for the doctors to come and explain what is happening. About 20 minutes later, Rebecca comes in and says, "Right, we are going to move him to a side room because a woman who was there has gone home." Suddenly, the wardrobe is open and all Jack's stuff is hurriedly packed and he is moved to the other side of the ward. It is dark on this side of the ward, but the room is quite bright. Rebecca and another nurse wheel Jack around in his bed. Then Jack's family goes into the room and sits down. We all sit in the room with Jack. Jack's brother Cam stands up and says, "Hi Jack, it's your bro here." Jack opens his eyes. His breathing calms when someone speaks to him. The family sits quietly around the bed, and the waiting begins.

Interaction 6: Visiting Helen, Oncology Ward—Side room

While I was visiting Helen today, she pointed to the window-ledge and said, "Look what Chris bought me." It was a small wooden man holding a heart in his hands as an offering. She said, "It is so I will have his love

forever.” Tears welled up in her eyes and in Chris’s as she said this. I said, “That is so beautiful Helen,” and she smiled. I was aware that there were tears forming in my eyes, too. I looked around this small sanctuary. There were lots of flowers on the window sill and a little teddy bear. Her room looked like a little haven. Patrick was sitting in the corner studying. I said hi to him and asked how the study was going, he said it was really good, and it was nice to sit here and study. He explained that he had worked last night, so Sandra had stayed the night with Helen and now she has gone home to have a sleep. I asked Helen when she was going home, and she said that they hoped to have everything set up by tomorrow and she was going to get a hospital bed and put it in the lounge so she could lie there and look at her garden. Chris said that everyone here had been great and they have everything set up.

Interaction 7: Visiting Daniel, Oncology Ward—Side room

I have arrived at the hospital to visit Daniel. He has already been moved to a single side room. . . . Family/whanau and friends move between Daniel’s room and the seminar room talking in quiet hushed voices. This pattern continues all afternoon. Two friends of Daniel’s are sitting in Daniel’s room and they begin quietly playing guitars and singing. I smile because Daniel had told me that when he was dying his whanau would arrive with guitars and sing. By late afternoon, the chaplain has arrived at the family’s request. He asks everyone to come into the room with Daniel. We all crowd into this tiny room and the chaplain begins to pray in Maori. Afterwards, everyone sings a waiata (song) together. Although there are about 15 people in the room singing, the noise level is kept very low and respectful. Once the waiata is finished, whanau members begin to drift out of the bedroom and back to the seminar room. A couple of them go home for showers.

7.5.2 Interactions in the chemotherapy suite

Again using the computer software NVivo 7 to aid analysis, I was able to establish that there were a total of 318 references to the chemotherapy suite in my field-notes. Out of these 318 references, there were 118 codes for “interactions” in the chemotherapy suite. The following extracts have been chosen as they represent a cross section of the type of interactions that are most common in the chemotherapy suite. Just as there was a difference between in the interactions that occurred on the two sides of the ward, there were also differences in the interactions that occurred in the two sections of the chemotherapy room.

In the section with recliner chairs, there was conversation and interaction between patients, staff and support people; in the room with the two beds, the interaction was primarily with staff or support people, not other patients. This difference was due to the beds being used only for people who were very ill.

Interaction 8: Alice in Chemotherapy Suite—Bed

Alice is vomiting again, she says she just wants to die. I say that I know she feels really bad. She is dry retching but very little is coming out because she was vomiting all the way in here today. . . . One of the nurses walks past and says, "Poor Alice." It's nice that people here are so sympathetic. Kevin comes over and says he will get her something for the nausea. He lets her know that he is there. Alice says she feels really, really bad. Kevin leaves to get the drugs. . . . Kevin comes back with anti-nausea drugs. Alice says that if this is what the end feels like, she'd rather just go now. She says she just wants to die. Kevin then says he is going to sort out Alice's dressing. Alice says she feels so tired. Kevin picks up the cotton wool bandage and says, "I guess we have some of this here." Alice tells him they do and it's in the dressing/storage room in the bottom cupboard on the right hand side. Kevin looks at me and shakes his head with a big smile on his face. Alice goes to sleep while Kevin goes to get dressing supplies. About 10 minutes later, he comes back and begins the dressing process.

Interaction 9: Daniel in Chemotherapy Suite—Recliner chair

Opposite Daniel's seat there is one woman attached to a drip who looks quite well and who is intently reading a book. She looks very familiar to me but I cannot place her. She is in her late 40s early 50s with a grey bob haircut and a smart working outfit. You get the feeling that she is just doing this in her lunch break. For some reason she seems totally out of place here. I just don't know why. The other seat opposite Daniel is empty for a while, but soon a very thin woman with long dyed hair comes and sits in it. She is quite loud and is making a real point of teasing all the male nurses and talking about how cute all the doctors are. She appears to be in her late 50s. She never stopped talking for the two hours that she was here. In the right hand section of the chemotherapy suite is a man sitting in a recliner with his wife sitting knitting next to him. He is reading a book. . . . Looking into the second section of the chemotherapy suite where the beds are, I can see a woman lying in bed with her husband sitting beside her holding her hand. She is almost skeletal, and looks very sick; she is hooked up to an IV line. The nurses are in and out and busy around everyone and very chatty.

Interaction 10: Helen in Chemotherapy Suite—Recliner chair

There is a lady opposite Helen who is here with her husband; she looks upset and he is consoling her. The nurses come to give her the chemotherapy and they read out her date of birth. Helen says to her that their birthdays are only a day apart. This starts a conversation between Helen and the other woman, Ann. Helen tells her that this is her second round of chemotherapy and she has had cancer for four years, but it has already spread to her lung, liver, and bones. Ann tells Helen that she has just found out that her liver cancer has already metastasized and although they can try to control it with the chemo, there is no way they can get rid of it. She begins to cry. Helen is very reassuring with her and telling her that she may get longer than she thinks because the chemotherapy has given her years longer than expected to. Ann's husband is listening intently as the conversation continues. The rest of the room is very busy.

Interaction 11: Daniel in Chemotherapy Suite—Recliner chair

One of the nurses, Robert, asks Daniel what he is doing on the weekend. Daniel replies that he would be watching the rugby, "The Springboks versus the All Blacks". Daniel asks another nurse who she thinks will win. She said we would. He said, "No, the Springboks will." Then Robert and the other nurse checked Daniel's date of birth and chemotherapy drugs. Robert explains that he is giving Daniel the Dexamethasone first. The man next door, who is sitting with his wife and is about 50 years old, says to Daniel, "You could go and play a game of rugby on that." Daniel laughs and the man asks him what he thinks the score will be for the game. Daniel replies, "I reckon it will be 38/24 to them." Robert talks to Daniel about the chemotherapy. It is often like this in here, a nice feeling of camaraderie among the patients and staff. I notice that humour is also used often by staff and by patients.

Interaction 12: Chemotherapy Suite

I walked through the chemotherapy suite today to find one of the palliative care team, and it was very busy in there, but there was a lovely feeling in the room. There was a television on in the suite, something I had never seen before. There was a game of rugby on television. The chemotherapy patients' chairs had been arranged in a circle, and the patients were all enthusiastically watching the game. Every now and then a nurse would ask them the score, or ask them what was happening. People were very animated and obviously enjoying the game, and appeared to feel a sense of connection with other chemotherapy patients, as they often spoke to each other.

Interaction 13: Helen in Chemotherapy Suite—Recliner chair then bed

I brought Helen in for her first chemotherapy treatment today, but she was vomiting when I picked her up and has continued to vomit since we arrived. She is in pain and feeling pretty lousy. On arrival, she sits in one

of the recliner chairs, but after a while, Doreen decides to move her to one of the beds in the other part of the room, so she will be more comfortable. The nurses are discussing which drugs to give Helen to control her nausea. Helen said to me, "I'm so sick of this that I just want it all to be over sometimes." Helen explains, "I've never felt like this before, I have always been so optimistic about the future, but now I just feel like giving up." I just sat next to her and listened to how she felt. I go back to get Helen's stuff from the seat area, and both the man opposite and the woman next to Helen ask me how she is doing. I say that she's not so great and may stay in hospital. They both appear to be genuinely concerned about Helen.

7.6 Systematic Analysis of Behaviour in the Two Sites

In conducting a systematic analysis of peoples' behaviours, Richardson (2003) considers the level of engagement in each setting, the role of people as participants or observers, intense and serene action as a result of the proximal characteristics of the material setting, and whether people are "on-stage" or "off-stage".

The chemotherapy suite exists for one purpose only: the delivery of treatment. Therefore, people who enter the suite are there for this reason. Consequently, behaviour is focused and purposeful. The patients need to engage with the staff in order to receive treatment, and often engage with each other as a flow-on result of conversation with staff. This is apparent in Interaction 10, where Helen realises the lady opposite her has the same birth date. The physical arrangement of the setting, chairs in close proximity, contributes to the level of engagement, as does the need for nurses to enter the close proximal space between themselves and their patients. The clinical setting and bland colours of the room appear to be almost irrelevant as the room is merely a backdrop to activity.

Conversely, the oncology ward is used for multiple purposes, from surgery, clinical tests, radiation treatment, and management of pain and chemotherapy side effects, and to care for the very sick and dying. Patients engage with staff in short bursts which are often spread out over days as opposed to hours. The physical arrangement of the setting brings people who may have little in common into contact for extended periods of time. An example of this is provided in Interaction 1, where Alice, who is in her 30s, is sharing a room with three women who are aged 65 and upwards. Other people's behaviours that may be tolerable when *visiting* a setting may be experienced as intolerable when *living* in the setting. An example of this type of behaviour is provided in Interaction 9 when a woman arrives for treatment; she teases the male nurses and talks for two hours. This situation can be tolerated in the short-term setting of the chemotherapy suite but could become intolerable if exposure to the behaviour continued for days. The proximal distance between patients in the ward is much greater than in the chemotherapy suite, and is demarcated by the curtain that surrounds the bed space. This space within the curtain is closely protected by those who inhabit it.

In the chemotherapy suite, patients are participants in the health care system, active recipients of treatment, and need to perform certain actions to receive treatment. Things are also being done "to them" that involve their participation. The design of the room also means that whilst participating in their own treatment, they are able to observe other patients. The close proximity of others contributes to patients being able to be interactive with each other.

The two sides of the ward have quite different material characteristics, which contribute to quite different behaviours and roles for the patients. In the shared rooms off the main corridor, patients are often observers. There are long periods of time where they are not engaged in conversation. The material setting is one in which private lives become public. Visitors with one patient are observed by all the other patients in the room. Conversations can be heard and there is little privacy in these shared rooms. Patients briefly become involved in interaction with hospital staff at times such as doctor's rounds, and they are observed by the other patients. There is nominal interaction between patients.

On the other side of the ward, where the single rooms are, patients are often very ill or dying, and, therefore, there are often family members present, as in Interaction 6, where Helen is in the small room with her husband and her son. There are, of course, situations or patients where there are few or no family members present. Because the patients tend to be very unwell, they are often heavily sedated or unconscious and, therefore, less interactive, as in Interaction 7, where Daniel is no longer conscious. Family members, who congregate in the hallway when their loved one is dying, become participants in meaningful, symbolic, interaction.

Action in the chemotherapy suite tends to be intense. There are usually other patients waiting for treatment in the waiting room, so the nurses are busy trying to treat their daily quota of patients. This contributes to the purposeful actions and, at times, a sense of urgency. The proximity of patients also adds to the sense of intense action. Patients are engaged and interactive, contributing to the activity in the setting. An example of activity

in the suite is provided in Interaction 12, where the patients had gathered around the television to watch rugby. Patients' physical appearance also adds a sense of life and colour to the chemotherapy suite space; they are dressed in their own clothes and have often come from another activity to their chemotherapy appointment. They are people in motion, people busy living (see Interaction 9), people hoping for cures, and people actively involved in the pursuit of this goal.

By contrast, action in the oncology ward changes throughout the day. It is busier during doctor's rounds which typically occur in the morning. It is quieter between 1pm and 3pm, as this is a time of quiet rest for patients. Between the hours of 3pm and 8pm, there is generally serene, as opposed to intense, activity within the ward. The serene feeling is maintained by the distance between patients, the nature of patients' illnesses, and the censoring of inappropriate "out-of-place" behaviour. On side of the ward where the single-bed rooms are, it is even more serene than along the main corridor, and there is often little activity unless a family have gathered for the dying of a loved one (Interaction 7). Even during these times, the serenity remains as family and friends tend to be most respectful of the health and well-being of patients in other rooms. Their actions tend to be slow, their words quiet, there is a sense of grief in the air.

Patients are "onstage" in the chemotherapy suite, and "offstage" in the oncology ward. The general activity and action in the chemotherapy suite could be likened to a fast-moving play. Activity is contrasted against the subdued clinical background, characters are aware of their role and purpose and are, therefore, engaged and interactive. Patients are dressed

for activity, dressed for being-in-the-world. By contrast, patients in the oncology ward are dressed in night-gowns and pyjamas; they are out-of-the-world of daily life. Daniel was the exception to this rule, when he went to the pub in his pyjamas. Action is spread out and slow moving. There are multiple sites of activity, single rooms, shared rooms, corridors, lounge, seminar room, nurses' station, as opposed to the openness of the chemotherapy suite. The walls and surroundings of the ward are also subdued, but the lack of interaction in the ward means that patients lying in bed often focus on the surroundings. Therefore, although both settings are similar in their clinical décor, one becomes the focus whilst the other becomes merely a backdrop.

7.7 Critical Contrast of the Interactions in the Two Material Settings

The ward consists of multiple spaces in which various interactions are occurring; therefore, experience of the ward through the eyes of patients in one room could be vastly different from patients in the next room. Within these multiple sites are regularly occurring micro-dramas, snippets of conversation and interaction, which remain invisible to people in other parts of the ward.

Both the chemotherapy suite and the oncology ward are waiting places, but the wait in the chemotherapy suite is quite different in length and activity level from that of the oncology ward. It is a wait of hours as opposed to days. During the time that patients are waiting, they are actively being treated, and there are multiple interactions with multiple patients. In the ward, patients wait often for days; they are waiting for test results, waiting to get better, waiting for operations, waiting for treatment, waiting to go home, waiting to be transferred,

or waiting to die. The staff-to-patient ratio is a lot higher in the chemotherapy suite than it is in the ward; this may contribute to patients' feelings of loneliness and abandonment. Interestingly, there are more boundary issues in the oncology ward, where the proximal distance between patients is greater, than in the chemotherapy suite where the proximal distance is much smaller.

Patients are not able to choose who they sit next to in the chemotherapy suite, or who they sleep next to in the ward. However, it is more difficult to live in the same space as another person for days than it is to sit next to someone for a few hours. There is a lack of privacy in both places, but this is not such an issue in the chemotherapy suite where patients spend limited time and have limited personal interaction with loved ones. The patients in the chemotherapy suite are often accompanied by a friend, family member, or Cancer Society driver. These support people sometimes stay with the patients in the chemotherapy suite, or they return later to collect them after the treatment. They are, however, present at the invitation of the patient. In the oncology ward, anyone coming during visiting hours can gain access to the patients. Although patients may be more unwell when they are in the ward than when they are at home, they often need to deal with more visitors than they would at home. This situation contributes to the sense of patients' private lives being played out in a public domain.

At the time of this research, the nature of the public health system in Aotearoa New Zealand is such that everyone with cancer, regardless of gender, race, ethnicity, religion, class, or ability has access to the same services and the same spaces within the public

hospitals. People who have medical insurance have a choice of whether to see an oncologist privately or through the public system. In some major New Zealand cities, chemotherapy and radiation are also available in private settings those who have medical insurance or who can afford to pay for treatment. However, there are often no doctors present in the evenings in private hospitals, and if a patient is very ill, they may be moved to a public hospital. This results in a diverse mix of people coming together in intimate and, sometimes, intense situations and having experiences that are often a matter of life and death. This adds to the emotional loading of particular interactions that occur within two specific settings in the public hospital.

Systematic analysis of behaviour in the chemotherapy suite and the oncology ward has provided a critical analysis which has exposed interactions that are “of” and “in” the two settings. Characteristically, interactions facilitated by the material setting of the chemotherapy suite result in the following behaviours: patients are engaged, they are participants and observers, there is intense action occurring in close proximity, and patients in the setting are onstage. In the oncology ward, however, patients are less engaged, tend to be observers more than participants, and there is serene action which is spread over greater areas of proximity and often shielded from other people’s eyes. Patients in the ward are offstage. The examples of interactions that have been provided in this study are merely snapshots of the type of interactions that occur in each setting, they are not an exhaustive account of interactions. These interactions were facilitated and maintained by the material settings in which they occurred, in this way, the setting was incorporated into the situation. Richardson’s (2003) final step in analysing interactions that occur in place is the

development of an image of the setting that has moved from being a preliminary definition of the setting to a “full exposition” of the interactions within the setting.

7.8 Image that Completes the Definition

Richardson (2003) states: “The final step in the process of incorporating the setting into the ongoing situation is the objectification of the sense of the situation upon the setting so that the setting becomes a material image of the emerging situation” (p. 85). Richardson proposes that the material image is what the ethnographer sees upon completion of their analysis. Initially, I spoke of people in these locations in objective terms, as simply “people” or “participants”. Once I considered their interaction within particular environments, I began to speak of them as “patients”. The use of this language reaffirms that they are “of” the setting—“patients in hospital”, as opposed to “people in the setting”. In a similar manner, the two settings became places for particular types of interaction, places imbued with meaning, not simply locations. Considering the two settings in light of what is now understood about the two locations, it is possible to formulate a statement, which, as Richardson suggests, explains the “overall meaning of the two places”.

7.9 The Overall Meaning of the Two Places

The chemotherapy suite, the hospital context, and the arrangement of the clinical space into closely placed recliner chairs and beds, sets the scene for interaction that is engaged, intense, and onstage. From that interaction, the implicit theme of treatment is reaffirmed in the image of the chemotherapy suite as a place for getting well, being healed, or cured.

The oncology ward, the hospital context, and the arrangement of the ward into separated spaces consisting of multiple-bed rooms on one side of the ward and single-bed rooms on the other side, characterises interaction that is disengaged, serene, and off-stage. From this interaction, the implicit theme of illness is reaffirmed in the image of the ward as a place of waiting. On one side, the patients are waiting to get better, to leave, to receive test results, to have treatment, or to be relocated. On the other side of the ward, patients and families are also waiting—waiting for bad news and waiting for death.

7.10 Conclusion: Contrast of the Two Images

The chemotherapy suite is a place where people go in an attempt to get well, to live longer; it is not a place to be ill or to die. In the chemotherapy suite, disease is being tamed, there is a triumph of medicalisation over death. On the whole, people tend to be dressed, ready for action, ready for living. There are exceptions, such as days when participants arrived for chemotherapy but were too sick to receive it. These were discussed in Interactions 8 and 13, where both participants were eventually transferred to the oncology ward. People come to the chemotherapy suite, however, holding hope in their outstretched hands, even those who have been told, as the participants were, that their cancer is incurable. They attempt to carve out days of extra time; time is viewed as a precious commodity to be extended at all costs. Participation in the chemotherapy suite means to be actively involved in the fight against cancer; if they do not participate, they will die. Sometimes people succeed, sometimes they do not. In contrast to the image of medicine that prevails in the chemotherapy suite, the image of illness and disease predominates in the oncology ward. The two places have almost opposite meanings, one is of treatment, the other of illness, and

yet they are inextricably linked. Having chemotherapy treatment can lead to side effects, for which patients are admitted to the ward. Not having chemotherapy can lead to cancer symptoms which also require admission to the ward. The tension is that being in one place can often lead to being in the other, even though the themes of the two sites appear to be mutually exclusive. The existential meanings of the two places create a dichotomy that is often unresolved in the minds of patients. By focusing on cure and treatment, the ill participants often neglected the need to consider death and dying. The eking out of more time, as occurs in the chemotherapy suite, often takes priority over the consideration of how little time is left.

People who attend the hospital “have two distinct realities in which to be” (Richardson, 2003, p. 87). In the context of the current research, the two realities consisted of the chemotherapy suite, with its image of treatment, and the ward, with its image of illness. These two social realities are components of the larger environment of cancer patients. The interdependence of the two realities and the tensions inherent in each contribute to the cultural milieu of cancer patients.

Having explored the locations that participants occupied during their journeys through palliative care, and their identity as people living with cancer, I will now turn my attention to the final part of the participants’ journeys; journeys within which their identity is once more transformed as they shift from being “people living with cancer” to “people dying of cancer”. These final journeys towards death will be discussed in Chapter Eight by further

exploring the experiences of the eight terminally-ill participants and 83 family members, who were involved in the research.

In a similar manner to Pettigrew's (1999) research, ethnography and grounded theory have been used in this study of participants' journeys from diagnosis to the end of life. Ethnographic methods have been used to collect thick, descriptive data. Grounded theory has then been used to analyse the data. The ethnographic account has yielded a significant amount of descriptive data relating to behaviour that occurred in certain places, at certain times, as well as behaviour that was of the environment and socially sanctioned. Similarities between behaviour in one place have been compared to behaviours in another place, and from this comparison, the theoretical categories of behaviour have emerged that were "in" and "of" the material setting. The core category of "time and place" has also emerged as I explored the participants' behaviour in their home environment in Chapter Six, and in this chapter, their behaviour in medical settings.

Chapter Eight

Journey's End

*Being witness to the journeys of these people
taught me that in embracing who we are
physically, psychologically, and spiritually,
dying is not so much about living in fear;
paradoxically, it's about finding a way to
integrate all of who I am—past and present—
into a new wholeness of who I am as a person.
Therein I find peace, compassion, and hope.
(Kuhl, 2002, p. 270)*

8.1 Introduction

One of the research aims developed from reflecting on personal experience and issues raised in the preliminary thesis proposal literature review, was to investigate how individuals and families “understood their decisions” about end-of-life care. This aim was developed with the preconceived notion in mind that people move towards death with the knowledge they are dying, and that their families also know this. I also assumed, from what I had read in the preliminary literature search, that people will have been told what their options for care are, and that they will be conscious and have enough time to make an informed decision about the care they are to receive. Reconsidering this aim in light of the data and a grounded theory literature review, I am now aware that this early aim implied that individuals and families “actively” make decisions about their end-of-life care. This suggests a certain amount of control based on access to clear information about the imminence of death. As I proceeded with the research process, I grew to understand that, in actuality, such information is frequently not provided, and awareness of the imminence of death is variable and fluctuates. In contrast to the themes from the preliminary literature

search, the themes that emerged during the research process and data analysis in this current study were more chaotic in nature. These themes highlighted the issues and difficulties inherent in end-of-life decision making.

This chapter explores these issues in light of the context in which the dying individual and his or her family make decisions about end-of-life care. In total, eight terminally-ill participants and 83 family members contributed to this chapter by allowing me to tell their stories. Data from the last few weeks, days, or hours of the eight participants' lives is explored in order to gain an understanding of the context for decision making. This is done in an attempt to clarify the physical, emotional, psychosocial, and spiritual context in which decision making is located. The major themes that will be discussed are: transition from chronic to end-stage cancer, awareness of impending death, the need for practitioners to accurately diagnose dying, access to information, preparedness for death, the need for disclosure of accurate prognosis, the components required to achieve a "good death", including deciding where to die, the environment in which the dying are located, family culture, and systems theory. Finally, I will briefly discuss the process I undertook as the researcher.

8.2 From Chronic to Late-stage Cancer: Approaching Death

All of the ill participants had cancer; therefore, their disease trajectories followed a similar although not identical path. Field and Cassel (1997), in their project "Approaching Death", discuss three simplified disease trajectories leading to death. Firstly, sudden and unexpected death; secondly, a steady and fairly predictable decline; thirdly, "fairly long

periods of chronic illness punctuated by crises, one of which may prove fatal” (p. 11). Field and Cassel suggest that patients and families in the third trajectory may not regard the ill person as dying. They further suggest that cancer patients who fall into the second disease trajectory can also be divided into two groups. They may be:

. . . imminently dying (i.e., likely to die within minutes to days) and those who are terminally ill but not thought to be ‘actively’ dying (i.e., having a life expectancy of days to months, sometimes years). The latter group may have a period of ‘chronic living-dying’ between diagnosis of an incurable illness and imminent death. (p. 28)

The second disease trajectory with its two subgroups, imminently and actively dying, along with the notion of chronic living-dying, can be usefully applied to the current research to provide a language for the discussion of participants’ process as they became more unwell and debilitated by their cancer. Two of the participants who were actively dying seemed to decline steadily over time as they approached death, and six seemed to have an experience of chronic living-dying punctuated by various crises, which moved them closer to imminent death. The language and terms I am using in this chapter are not words that I heard used in health settings to explain a patient’s prognosis. The terms “terminal illness”, “end of life”, “imminently” or “actively dying”, and “chronic living-dying”, are more likely to be used during case presentations, conferences, and in the literature.

I also rarely heard the words “dying” or “death” used by health professionals. Two terms I did hear used in the hospital, were “late-stage” and “end-stage” cancer. The careful and selective use of language may be an attempt to maintain a patient’s sense of hope. Germain (1991) argues that not everyone wants open and honest communication about imminent

death, and that the power of hope, and the non-acknowledgement of impending death, often referred to as denial, may serve important functions. I noticed during the data collection of this research that participants would hold onto every word spoken by health professionals and attempt to extract what they called the “hidden” or “real” meanings from them in later conversations.

Another term, “approaching death”, is used by Field and Cassel (1997) when they talk about patients and families in this latter phase of illness. Field and Cassel suggest that patients approaching death are those expected to die within days or months. They also argue that the term “approaching death” can be used to describe the families’ process as well as that of the person who is dying. This term is quite fitting for the current research as it is psychosocial in nature, as opposed to the more pathological terms that denote the physical or medical process.

8.3 Awareness of Approaching Death

Factors that contributed to participants’ awareness of approaching death included decisions and discussions about treatment, health crises, admissions to hospital, hospice, or care facilities, and their ability to care for themselves and remain independent. Conversations the participants had with health care professionals, families, friends, and myself as the researcher, also contributed to their understandings of approaching death. In some situations, the participants voiced this awareness, and in other situations, their actions provided information about their awareness.

The participants' process of approaching death was explored by reviewing each individual's transition from chronic living-dying, to active dying or imminent death. This process often began with the ill participant's presentation to a health provider following the development of worsening symptoms, which emerged as a crisis. In a similar manner to the disease trajectory suggested by Field and Cassel (1997), participants often experienced the onset of new symptoms, experienced as a crisis, or an escalation of existing symptoms at the start of their transition to late-stage cancer. The presence of these symptoms was closely followed by a visit to the participant's GP who referred him or her to the hospital accident and emergency department (A&E), or advised a non-referral visit directly to accident and emergency, the oncology department, or the community palliative care team.

Six of the eight participants who later died presented to the accident and emergency department due to deteriorating health. Five of the six were admitted to hospital. Jack was admitted to hospital three weeks prior to his death, where he continued to deteriorate. Jack's family was not aware that he was dying, but was aware that his health was deteriorating. The family did not discuss where Jack wanted to be at the time of his death. Jack lost consciousness three days prior to his death, and was relocated to one of the small side rooms in the oncology ward. Jack's family was told that he was dying, so they gathered in the room and hallway and maintained a bedside vigil until his death in the early evening of the third day.

Elisabeth was initially admitted to the oncology ward, and she and her daughter Penny made plans for her to go home to die. Although Elisabeth never admitted that she knew she

was dying, Penny knew as Elisabeth's oncologist had told her this. Penny had originally been told that Elisabeth would live for about another six months, and was upset when she was told that she now only had three weeks to live. Penny took her mother home to spend their last few weeks together, and she also alerted the family to the fact that Elisabeth was now dying. Elisabeth spent time with her daughter and grandson until her death in the early evening of her third day at home.

Daniel was admitted to hospital after presenting to the accident and emergency department, and although he planned to go home, his health deteriorated suddenly, and he became unconscious on his third day in hospital. Daniel's family knew that he was dying because Daniel had been told he was and had let all his family know. However, they were not prepared for his death to occur as soon as it did, and believed that they were going to have a few more weeks to spend time with him at home. Daniel died in hospital three days after he was admitted.

Helen was admitted to hospital and her family all knew that she was dying as they were present when the doctors told Helen and Chris that the cancer had progressed rapidly and there was nothing else they could do. Helen wanted to go home to die, and she and Chris worked towards this goal. After three days, Helen was sent home to die. She and her family believed that they would have another two or three weeks at home to spend time together. However, on Helen's first night at home she deteriorated and died the following afternoon.

Joan was admitted to hospital six days prior to her death. She was originally placed in a side room, and when her health improved, she was moved back to the main ward. On the fourth day, she deteriorated and was relocated to a side room. Joan's family was not able to accept that she was dying until she told them she was. The family had tried asking her doctor for more information but had not received a straightforward answer. At this stage, Joan's family was planning to take her home, but because she lost consciousness, they alerted the rest of the family to the fact that she was dying. On her fifth day in hospital, Joan's family gathered to say goodbye, and some of them stayed with her during the night. She died in the early hours of the next morning.

Alice attended the accident and emergency department one evening in a miserable and dishevelled state. She was seen by two doctors and discharged home to be seen the following week by her oncologist. Neither of the two doctors diagnosed Alice as dying and she died within hours of leaving accident and emergency. Alice's husband Dennis did not believe that Alice was dying and was unprepared for her death when it occurred later that same evening. Her family was not given the chance to say goodbye to her, and they were all shocked when they heard that she had died.

Tom had had regular contact with the community palliative care team while he was at home and his family contacted the team when his health deteriorated. The team arranged for him to be admitted to the hospice, and let his family know that he was dying. Tom's large family gathered and maintained a vigil that lasted for three days. Tom died in the early evening of the third day.

Billy was in long-term care as he approached the end of life. His primary focus in the previous year had been to prepare himself spiritually for “leaving his body”. Billy believed that the soul never dies; it transitions out of the current body and into another body. Therefore, he always used the term “leaving the body”. He was aware, as he approached death, that he was deteriorating daily and he was very well prepared. He had also helped his family and friends prepare for his death by talking about it openly and honestly. His sister stayed by his side for many months in the unit and slept on a small mattress on the floor. His family and close friends had time to gather and be with him the night he left his body. Billy “left his body” while praying; this was the goal he had worked towards for the previous year, to die conscious and in prayer.

As discussed in Chapter Two, the literature review, as early as 1959, health professionals accepted that the quality of care provided for the dying often depended on the availability of capable family members who were open and honest about their loved one’s prognosis. In fact, from the very beginning of the hospice philosophy, the family’s role as caregivers was regarded as an integral component of end-of-life care (Saunders, 2001). The Whare Tapa Wha model (Durie, 2001) includes family and extended family (taha whanau) as a vital structural element in the care of the dying person. In Kirk et al.’s (2004) study, all 35 family members, who knew that their family member was dying, thought that open and honest communication about prognosis was important.

A major theme that developed in the process of data analysis in this current study was the varying levels of awareness among the families of the participants that their ill loved one was declining physically and that he or she was approaching death. The data were reviewed

in light of the above literature and other studies which suggest that openness about death and dying, and awareness of approaching death, is desirable (Cohen, 2003) and necessary for the family's decision-making process and choice about where their relative should die (Ellershaw & Ward, 2003). One of the barriers to this is an inability to diagnose dying in order to meet the needs of the dying person and their family (ibid).

8.4 Difficulties in Diagnosing Dying

One of the issues highlighted by the research was late referral to palliative care services, including the community and the hospital-based teams. Smith (2000) suggests that this late referral pattern occurs because doctors do not know how to diagnose dying. The inability to diagnose dying was evident on the last day of Alice's life where she attended the accident and emergency department and was discharged home in the early evening to be seen by her oncologist the following week. Alice died that night in bed at her home. Helen was seen at home prior to her death by two palliative care nurses; her family was told that it was unlikely that she would die in the next couple of days; she died one hour later.

Tom's family was told to go home from the hospice and rest as it was unlikely Tom was going to die in the next day or so, because his heart was very strong and he could live up to two weeks. Many family members left the hospice and Tom died three hours later. As discussed in Chapter Two, the literature review (see section 2.6.2), as well as contributing significantly towards a distressing death, the inability to diagnose dying also contributes to a more complicated bereavement for unprepared family/whanau members and friends (Ellershaw & Ward, 2003; The et al., 2001). This highlights the need for a more adequate diagnosis of dying in order to meet the needs of the dying and their families. In Joan's and

Jack's cases the doctors were able to diagnose that they were dying; however, they did not say those actual words to the families. I listened as Joan's family asked Joan's doctor if she was dying. They asked him in five different ways and yet he did not confirm what everyone in the room knew to be true. These situations raise the issue of the need for access to clear information as death approaches, as well as throughout the ill person's journey.

8.5 Access to Information

It is noted in the *New Zealand Palliative Care Strategy* that: "There is insufficient information provided to patients who are dying and their family/whanau about treatment and palliation options and the services and providers available to meet their choices" (MOH, 2001, p. 45). One of the issues I noticed often throughout the fieldwork, most importantly at the end of life, was the difficulty families experienced in gaining access to information on a daily basis. This problem came to my attention when Jack's family asked me to give them daily updates on his health. Initially, I felt that there was something very wrong with the fact that I had access to information that Jack's family did not. Over the course of the fieldwork, I began to see this situation occur with most of the participants who were hospitalised for periods of time. It appeared that the primary reason I had access to information that families did not have was because I was often present for doctors' rounds.

Doctors' rounds typically occurred in the morning, so I would often arrive at the bedside of one of my participants around 8am. At times, I would be there up to four or more hours before the doctors arrived. At other times, they arrived not long after I did. Occasionally, they would arrive before I did and I would miss the round. The majority of the participants

were under retirement age, and their partners were often at work or occupied during the day. This meant they were unable to sit with the ill participant for hours in the hope that they might see the doctor to get updated information. For example, Jack's wife Betty came in to visit Jack during her lunch break; Alice's husband was unable to visit her during the day as he worked outside the city; Elisabeth's daughter had to take care of her son and get him to school in the morning, as well as look after the family home, so she was unable to be at the hospital first thing in the morning. There were several other factors that also served to inhibit the family's access to information.

Firstly, the ill participant was often heavily sedated or very unwell and was, therefore, unaware or unsure of what they had been told by the doctors during rounds. This was highlighted by participants asking me if I could find out what was happening when I arrived to visit them. When the ill participant did not know what was happening they could not provide any information for family members. I was witness to many conversations concerning the choices between further intervention or palliative care, and in the majority of cases, the participant, an hour after the conversation, was unsure what had been said.

Secondly, when family members were present, the doctors would ask them to leave during the consultation. I was often given permission to be present as the doctors knew that I was conducting research. I would record what the doctors said as accurately as possible and compare this information to the information provided by the ill participant to the family members. In many cases, a large amount of detail was not given to families, but the general

message was conveyed. In other situations, the information given to families by the ill participant was incorrect.

A similar situation occurred if family members were not present during oncology outpatient appointments. This situation was also common due to the variable time spent in the waiting room prior to the appointment, and this often created difficulty for family members who had taken time off work to attend. The ill participant repeating uncertain information was particularly disconcerting when the information was about adjustments to medication. In situations where the ill participant did not accurately reflect my record of the information given by the doctor about medication, I would draw the family member's attention to the inaccuracy and ensure that they checked the information with the doctor. The primary vehicle for family members to get information about their ill relative was to make an appointment with the oncologist or other health professional, or to request a family meeting. However, these appointments or meetings did not occur often, and as the participant's health was often deteriorating daily, families wanted access to more readily available, ongoing information. This issue, along with others, may be addressed by the appointment of care-coordinators as suggested in the *Palliative Care Strategy* (MOH, 2001). The lack of clear and concise information appeared to contribute to participants and their families being unprepared for death.

8.6 Preparedness for Death

One of the major themes pertaining to the end of life that arose in the data analysis, was participants' preparedness for death. In considering whether participants were aware of their imminent death, I decided to examine the data relating to one month prior to their

deaths and review what each of them had understood about their prognosis and their health at that point in time. In a sense, this review highlighted each participant's focus on living, and their focus on dying. Kuhl (2002, p. xxi) coins the phrase "living with dying" to explain a person's journey after a terminal diagnosis, a term that can be aptly applied to the research participants in this study. I conducted the review of the data with the following questions in mind: One month prior to their death, did the participants, who had lived with dying for various amounts of time, know that their death was close? Were they prepared? Did they know what to expect? Had they done all the things they had wanted to do, said all they needed to say? Had they accepted that their death was inevitable and imminent?

By conducting this review, I found that three of the participants were prepared for death one month prior to their death and five were not. The primary factor in achieving a level of awareness seemed to be the individual's personality, a previous serious illness, and their acceptance of their current diagnosis (this is discussed further in Chapter Nine, see section 9.4.2). Other contributing factors were the information given to them by health professionals, and family members' awareness. The three prepared participants had done all they wanted to do and said all they wanted to say. One of the compounding factors in participants' awareness of their imminent death was the conversations they had with health professionals about their prognosis, and the responses, or their understanding of the responses, which were given.

8.7 Prognosis

The review of the data relating to participants' lives one month prior to their death indicated that there were two points in the participants' journeys where the topic of prognosis arose. The first point was at the initial diagnosis of a terminal illness, and the second point tended to be much closer to the end of life. Prognoses tended to be given in response to the individual or family wanting to know how much time they had left. I conducted a further analysis of each time period in the lives of the eight participants. In considering the initial prognoses given to the participants at the time of diagnosis, it would appear that four of them were optimistic. Jack's prognosis was 12 months, he lived half of this. A similar timeline occurred with Alice who was given 20 months and lived nine-and-a-half months. Dennis was given eight months and lived six-and-a-half months. Billy was given a particularly optimistic prognosis that indicated that he may live for several years or until old age; he lived for just over one year from that prognosis. To my knowledge, three participants, Elisabeth, Helen and Tom, did not receive an earlier diagnosis or prognosis. Another participant, Joan, was given a fairly conservative prognosis of two months and lived for seven. In summary, therefore, it appears that when a prognosis is provided at the point of diagnosis, it tends to be uncertain. There are also apparent problems with providing an accurate time frame near the end of life.

As death became imminent in its approach, some of the participants were given a reasonably accurate prognosis. Daniel was told that he only had days to live and he died two days later. Elisabeth's daughter said that Elisabeth had been told that she only had two weeks to live; she died one week after being given this news. Billy's family was told that

he was in his last few days and he died two days later. Jack was not told that he was dying, but he believed that he was and spoke about this with his social worker and his family. There were also instances where the prognosis changed rapidly in the last week of life; this still left the individual and family unprepared. Helen was told she had anywhere from two to 30 days left to live; six days later her family was told that she had more than two days left. Helen died one-and-a-half hours after this was said. Overly optimistic prognoses were also given at this stage in the participants' journeys. Joan was told that she would be discharged in three days time to go home for her last few weeks. She died three days later, on the day she was hoping to be discharged. Tom's family was told that he could live for another week, but he died three hours after they were told this. Alice asked her oncologist if she was in her last days, and her oncologist replied that she would be surprised if that was the case. Alice died 16 days after that conversation.

There are a number of questions raised by the issues around prognosis. These include:

- How can timely access to appropriate palliative care be put in place when prognoses are so uncertain?
- How can an appropriate balance of treatment and palliative care be arranged so that there can be effective pain and symptom management at the end of life?
- When is it appropriate to have discussions with the dying person and their family so that they can make informed choices about where to die, and with whom?
- How can families and the person who is dying be better prepared at the time of death?

- How can death be more precisely diagnosed in order to meet the needs of the dying person and their family?

8.7.1 Uncertainty of prognosis

The timing of referral to palliative care is confounded by the uncertainty of prognosis and the difficulties in diagnosing dying. This issue is raised by a number of authors (Covinsky, Eng, Lui, Sands, & Yakke, 2003; Levenson, McCarthy, Lynn, Davis, & Phillips, 2000) in relation to death in older population groups. It is also discussed in relation to physicians' inability to accurately predict the time of death (Workman, 2007). A study of "365 doctors and 504 hospice outpatients found that only 20% of prognoses were accurate. Most predictions (63%) were overestimates . . . 17% . . . were overpessimistic" (Christakis & Lamont, 2000, p. 473). The authors state that "prognostic error is widespread" (p. 469) and is more common when the prognosis is made by less experienced doctors and when the doctor knows the patient well. It was also discovered that the most likely group of patients to receive overly optimistic predictions were cancer patients.

In relating this information to the analysis I undertook of the participants' prognoses, I found that each participant received at least two prognoses throughout their journey; one participant received three, which makes a total of 17 prognoses overall. As previously mentioned, some of the prognoses were given at diagnosis, some at the time of transition to late-stage cancer, and some as the participant approached death. Of these 17 prognoses, 14 were over optimistic and three were over pessimistic. Interestingly, the three participants involved in this study who were prepared for death, had each received one over-pessimistic

prognosis, as well as at least one over-optimistic prognosis. The remaining five participants who were not prepared for death were all given over-optimistic prognoses at least twice during their illness. A study that investigated the relationship between treatment preferences and prognoses also found that cancer patients, who had over-optimistic views of their chances of surviving, requested more aggressive treatment than those who did not (Weeks et al., 1998).

Greater prognostic certainty may also contribute to less aggressive treatment and a greater focus on palliative care and symptom management. Having a more focused approach to palliative care and providing increased access to social work and counselling support would have the flow-on effect of encouraging and supporting discussions about the end of life and preparedness for death. As I have previously stated, the prognosis given by health professionals contributes to the patients' understanding of their disease trajectory and provides clues about how long they may expect to live. To achieve more accurate guidance from individuals and their families about their needs if they are dying in hospital, Workman (2007) developed a five-step sequential tool for communicating with patients and families about treatment goals and outcomes. The five steps in the process are: 1. Deciding on treatment plans and goals; 2. Reevaluating the treatment; 3. Making informed decisions when treatment fails; 4. Withdrawing treatment and using symptom control; and 5. Managing requests for further treatment. Use of a tool such as Workman's would address many of the issues raised in this chapter.

Parkes (1972) argues that research instruments which provide a fairly accurate prognostic score need to be promoted so that individuals and families are more able to access timely palliative care and are more likely to be prepared emotionally, spiritually, and physically for death. Utilisation of these available tools would address many of the questions I have raised, such as: “How can timely access to appropriate palliative care be put in place when prognoses are uncertain?” It would also appear to answer a number of the other questions I have raised. If prognoses were more precise, it would be easier to achieve an appropriate balance of treatment and palliative care so that there is effective pain and symptom management at the end of life. If an individual and his or her family knew that the ill person was approaching death, they would be able to make informed choices about where to die, and with whom. A more accurate prognosis, combined with access to clear and concise information, would assist individuals and their families to be better prepared at the time of death.

8.8 The End of Life

The bedside vigils that occurred as participants neared death and family members arrived from various places are now explored. In my field-notes, I began to refer to this waiting time as “entering the twilight zone”. It is a timeless period where the outside world ceases to exist. Family members leave their homes, their jobs, and often their partners and children, and enter into a seemingly timeless vigil. The lights in the rooms are always on regardless of the hour of day. The family is present and there is always someone awake and on watch, ready to alert the rest of the family when the time comes. No-one wants to leave in case they miss the moment of death. When the dying process is lengthy, families return

home in shifts, clutching cell phones, often to shower, have quick naps, and return. Then there is the “changing of the guard” as others take their turn to leave. There are often family members who refuse to leave the dying person’s bedside, and they are cared for by other family members who bring them food and changes of clothes. At times, it feels as though everyone is sitting “holding their breath”, and at other times, there is chatter, laughter, tears, and reminiscing.

The theme, “the end of life”, is now discussed by drawing on the participants’ experiences. I have presented a synopsis of this time period from each participant’s and their family’s journey. These extracts will be presented intact and analysis will follow the last story. The themes woven through the discussion are: death with dignity, the good death, home aids and support, where to die, and spirituality.

Two days prior to Elisabeth’s death, she was at home, had had a very difficult night and was in a lot of pain. A nurse from the community palliative care team came to see Elisabeth and brought an air mattress that would alleviate the pain caused by pressure points. She also brought a prescription for morphine and reviewed Elisabeth’s pain medication. She was gentle and caring towards Elisabeth and her daughter Penny. Penny also managed to hire a nurse aid whom she knew. She was able to apply for the 28-day carer allowance in order to pay the nurse aid. The nurse aid was also very gentle, competent and caring towards Elisabeth, and supportive of Penny. Elisabeth died peacefully at home where she wanted to be, she had her family with her, and she was comfortable and free of pain.

Jack became unconscious the day prior to his death. He was still experiencing quite a lot of pain, even though he was heavily sedated. His nurse discussed the difficult decision of having to sacrifice consciousness for better pain management. Jack was quite distressed; even though he appeared to be unconscious, he let out small moans, he was sweating profusely and grimaced as he experienced waves of pain. Jack was relocated to one of the side rooms on the other side of the oncology ward, and his family stayed with him throughout this time. Jack and I had talked about where he wanted to die, and he thought that it would be better for him to stay in the hospital. He did not discuss this with his family. Jack knew the day prior to becoming unconscious that he was not going to live. He said that he accepted that now and he was glad that he had spent some time over the previous months reviewing his life and making peace with his family. He updated his will and gifted some money to his children. Jack and I never talked about his religious or spiritual beliefs. Jack's death was laboured as he continued to experience pain and discomfort. Members of his family became quite distressed watching him suffer and experienced his death as a relief from this suffering.

Daniel became unconscious on the day of his death; this was the day he had arranged to go home to die. Daniel's social worker took me aside when I arrived at the hospital and told me that Daniel had gone downhill very quickly and it was likely that he would die that day. She explained that he had not signed his will and she did not think he would regain consciousness. She asked me to give his will to his wife, which I did when Emily arrived in the late afternoon. The family had been unable to make contact with Daniel's wife during the day. It was unusual for her not to be there as she had been beside Daniel every step of

the way. However, Daniel had deteriorated very quickly and Emily was not expecting him to die so soon, even though the doctors had told them to expect this within the next few days. Daniel was in a single room at the entrance to the ward, but was then moved to the room at the end of the ward, so that his large extended whanau could also use the seminar room to gather in (see Chapter Seven, section 7.3.2). Daniel was sitting in a recliner chair and was well attended by his large extended whanau. There were many prayers said by his whanau, his aunty and the Maori chaplain. Once Emily arrived, she stayed by his side until his death in the early evening.

Alice attended the hospital accident and emergency department and was discharged home. Her husband Dennis and I helped her into bed; she took her medication and fell asleep. Dennis explained to me the next day that she got up about 2.30am and went to the toilet. He had helped her, but she had fallen against the wall in the toilet and she could hardly walk. He said that he helped her back into bed. She was really cold, and he told her to snuggle up and he gave her a cuddle. He thinks that she probably passed away about 3am or 4am, but he was asleep, and when he awoke the next morning at 8am he thought Alice was still asleep. He sat and watched television for a little while and was surprised when she did not wake up. At that point, he felt her face and realised she was cold. Dennis was in shock as he had not accepted that Alice was in her last days. Because of this shock, he could not comprehend that she had died, he needed someone to tell him. Dennis called me and he also called an ambulance and the community palliative care team. The ambulance asked Dennis numerous questions and said that they did not send an ambulance when someone was deceased. The community nurse arrived at the house and explained to Dennis

that Alice had been dead for quite a few hours. I arrived shortly afterwards, and Dennis talked to me about the shock he had when he realised that Alice was dead.

Three days after Joan was relocated to a side room, she began to slip in and out of consciousness. One of her sons arrived and spent time with her talking about the past. Another son, whom she had not seen for over a year, also visited her at the hospital on her last night. They had been estranged for that period and Joan wanted to see him before she died. He came with his partner and son, and he and Joan made peace with each other and said their goodbyes. Joan's daughter and her husband had also arrived to see Joan and had managed to spend some time with her. Joan's remaining son did not come to see her before her death as they had been estranged for over five years and the wounds were deep. Joan still spoke of him, though, and said she hoped he would have a good life. Although initial plans had been made for Joan to return home, she knew when she was relocated to the side room that she would not be going home. She was in hospital for a total of 12 days prior to her death. Because she was comfortable and her mouth ulcers had been treated, she was able to speak and to have important conversations with her children and with her partner Bill, who had cared for her throughout her illness. She was also able to talk to her sister Maria, who had been with her through this journey. She died a peaceful and dignified death, free of pain, and at peace. Bill was with her at the end.

Helen was discharged from hospital as she wanted to go home to die. The hospital had arranged home aids, such as a commode and a hospital bed, which was set up in the lounge so Helen could be near her family, and look out at her garden. Her husband Chris explained

to me, when I arrived at their house on a Friday morning, that it had taken all the previous day to arrange for Helen to be discharged, and they had had only a few quiet hours together in the evening before Helen began to deteriorate. He told me that Helen had a very uncomfortable night and the community palliative care team had been called several times since 5am but no-one had as yet arrived. Helen's daughter had been beside her all night, endeavouring to bring her comfort. Helen's son had to go to work so he was not there when I first arrived, but he came home about lunchtime. Helen was obviously distressed and wailing loudly. As I talked with her, she said that she was in pain and angry that she was dying so soon. She said, "*I feel ripped off.*" Her family members were all quite distressed that Helen was so unsettled, and so uncomfortable. At 10.45am the palliative care nurses arrived and washed Helen and set up a morphine pump. Helen continued to wail and the nurse told her that there was no need to make "such a fuss". When the nurses finished taking care of Helen, they came into the dining room where the family and I were waiting. One nurse told the family that the morphine pump should start to work in about 30-60 minutes. The family asked questions about what they should do over the coming weekend if Helen was unsettled. The nurse explained that she did not think Helen would die over the weekend as she was still quite strong. Helen died within the hour. Her son was with her, but her husband had gone to get her prescription filled, and her daughter had gone to the airport to collect Helen's mother. They were quite shocked when they returned home to find that Helen had died.

Tom was admitted to the hospice three days prior to his death. His extended family was with him during this period of time. I saw Tom at the hospice on his second and third days.

The members of Tom's large extended family were all with him at the hospice, and they spent time sitting with him before wandering out to the foyer area to join the rest of the family. Tom's wife said that Tom was semi-conscious and distressed and that she did not know what to do to calm him. Tom's family arranged for a priest to come to visit Tom and to give him the last rites. Tom's mother sat and prayed beside his bed, and she was comforted by visits from Catholic nuns. Tom was moved to a larger room late in the afternoon on the third day of his admission to the hospice. Although the nurses said that Tom might live for another two weeks, he died in the early evening of that day.

Billy had been living in a specialist palliative care unit for the past year. He moved into the unit after he and his wife separated. Billy was unable to care for himself as he had become very weak and was in pain. Billy deteriorated slowly over the course of the year, and he continued to focus solely on his spiritual life. He was very well prepared for death and even came to welcome it. He had given away all of his possessions and prepared himself emotionally, physically, and spiritually for the end of his life. He often referred to himself as being a passenger waiting in a departure lounge wondering when his plane was going to come. Billy was unconscious for the day and night before he "left his body". Although he had been unconscious, he began to pray out loud at the moment of his death. His family watched in amazement as he prayed to his beloved God, and then slipped peacefully away.

8.8.1 The environment in which death is occurring

In summary, six of the eight participants presented at the main hospital accident and emergency department at the onset of the major crisis that marked their transition to late-

stage cancer. One was discharged home and died there, with close family unaware that the death had taken place. Five were admitted to hospital and as it became obvious that the health of each of these participants had deteriorated, the family was called and began to gather in the hospital. The seventh participant was admitted directly to the hospice and his family began to gather there. The eighth participant was living in a long-term palliative care unit for the last year of his life. His family and friends gathered as he approached the end of life. These events raise issues pertaining to the environment in which the dying are located, and the environment in which families gather. I am aware that the *Palliative Care Strategy* (MOH, 2001) promotes dying at home which might appear to make this issue redundant when it comes to funding palliative care services. However, in actuality, most of the participants in this study died in hospital.

Families gathered in the hallways outside the single rooms on one side of the oncology ward (as described in Chapter Eight, see section 8.8.1) and they gathered in the foyers outside the ward. Approximately five people can be seated in one of the single rooms, but space is limited. The result of this is that family members are often standing outside of the room and have little privacy in which to experience their loss and grief. The larger the group, the more significant the issue. For example, in Daniel's case, there were 28 family/whanau members; staff working in the hospital system provided an alternative space for whanau in the seminar room. This issue is also apparent in the hospice when large families/whanau gather. In Tom's case there were 23 family members present. The hospice space was admittedly larger and more accommodating than the small hallways in the oncology ward, but the gathering of a large family/whanau group appeared to create a level

of disruption within the hospice environment. The tea and coffee area and the lounge were quite small and Tom's large family easily occupied both those spaces as well as outside table areas and the central foyer area. This left little space for family members of the other patients to gather.

In medium-sized families, such as Jack's, there were an average of ten family members present at any one time, and in Joan's family there were from five to eight members present when she died. As these were not large groups, they were not offered the use of the seminar room, but they were too large a group to all fit in the single room. Therefore, both Jack's and Joan's family spent a significant amount of time standing in the hallway, outside the bedrooms in which their family member died. A similar situation occurred in the palliative care unit where Billy had been living. His family and friends often numbered 12 or more, and because the room was very small, the family was given the use of a comfortable lounge area. The culture of the unit was very different from the culture of the oncology ward. In the ward, people were admitted as the result of a health crisis or because they had deteriorated and were approaching death. By contrast, the place where Billy was living was a specialist private care unit and people were only admitted if they were expected to die within a relatively short period of time. Billy was an exception as he had lived longer than was expected at the time of his admission.

As I arrived at the oncology ward to visit participants, I would often glance down the first corridor where the single rooms were located and see family members milling in the hallway. It was a clear sign that the person in the room was approaching death. This fact

was known to the patients on the other side of the ward, who understood the meaning of these gatherings and were deeply affected by this sight. They would tell me when I arrived that someone was dying, and they would seem to lose a little hope each time. Understanding this meaning attached to the single rooms, participants were aware that when they were to be relocated to the single rooms, it would be because they were approaching death.

Whilst the hospice provides larger and more comfortable rooms for family members to gather in, there were only 16 beds in the hospice which caters for a large geographical area with a population of 462,783 (Te Ara, 2008). The figures provided in the *Palliative Care Strategy* (MOH, 2001) indicate that of the people who died of cancer in hospital in 1996, 35% were Maori, 42% Pacific peoples, and 39% of all other ethnic groups. Of those who died in hospital from other diseases apart from cancer, 39% were Maori, 45% Pacific peoples, and 41% all other ethnic groups. (The fact that percentages add up to over 100% is due to the fact that some people will identify with more than one ethnic group). Maori and Pacific families tend to be larger and closely connected and, therefore, these figures indicate that there is a clear need for improvement in hospital facilities for the dying. This need is not mentioned in the *Palliative Care Strategy*, and is not classed as essential to palliative care services for the dying. This may, in part, be attributed to the fact that those in need are not actually patients but family members and the *Strategy* has a relatively individualistic focus on the needs of the dying.

Hospital services tend to be provided solely for patients. Statistics do not, therefore, provide any indication of the large number of family members or loved ones whose needs are not met as they congregate in hospital corridors and around the beds of the dying. There is, however, some discussion in the *Palliative Care Strategy* of the needs of specific population groups, such as “Maori, Pacific peoples, people with disabilities and non-malignant disease, people under the age of 65, and children” (MOH, 2001, p. 12). The mention of these groups is followed by the comment that “it is important that palliative care services be flexible enough to ensure that all needs are met” (p. 12). The reality is that the needs of any cultural group cannot be met if resources, such as space, are not available. This issue is further discussed in relation to ecological systems theory.

8.9 Family Culture and the Ecological Perspective

Drawing on ecological systems theory as discussed in Chapter Three (see section 3.6), it becomes apparent that as participants approached death and family members (family system) arrived, often in large numbers, there were a range of responses made by the health system. Pincus and Minahan (1973) suggest that there are three possible responses between systems: collaboration, bargaining, or conflict. Although their conclusions were made 30 years ago, their analysis is still relevant in the context of considering the dynamics of interchanges between systems. Many examples of collaboration between the person and the environment can be found throughout the data analysed in this study from the beginning of the participants’ journeys to the end of life. However, examples of bargaining or conflict did not tend to emerge until late in the participants’ journeys. It was at the later point of the journey that families who had not been enculturated into the health system made their

wishes for their dying family member known. The ill participants had conformed to, or collaborated with, the health system in order to have their needs met, but at the end of life, it appeared that the health system had to bend to meet the needs of the family system.

Depending on the culture of each family, for example, where large numbers of extended family and whanau were present—often for days on end, their needs included: privacy; to play certain types of music; to burn incense; additional beds and bedding; the use of rooms normally used for different purposes; seats in corridors or hallways outside rooms; a place for family members to eat; and the use of hospital property, including towels, hand wash basins, and pyjamas. When members of either system were unwilling or unable to bargain or collaborate to meet the needs of both systems, conflict arose. Successful collaboration occurred in Daniel's case when his whanau were provided with the seminar room. Whanau were also assisted to begin Daniel's tangi/funeral on the ward immediately following his death. It is customary for Maori to begin the tangi as soon as possible following death. Because of this collaboration, the cultural needs of Daniel and his whanau were accommodated, at least to this important extent. An example of bargaining which resulted in a successful outcome for the health system, but a less than adequate outcome for the family system, relates to Tom's death and his family's cultural needs. Tom had a large extended family/whanau who wanted to be present when he died. The hospice found the presence of so many people too disruptive and suggested that some of them should go home and then take turns spending time with Tom. This resulted in many of them not being present at the time of his death.

8.10 The Researcher

As the participants approached this crucial time in their living-dying, I gained an increasing awareness of my own parallel process. The culmination of each participant's life was also the culmination of my experiences with them. I was now part of the experience and as I struggled for months to write this final findings chapter, I began to understand my parallel journey and how telling the participants' stories was in many ways telling my own. My journey is also part of the data, and although I had become aware of this emerging pattern during the data analysis, I had initially thought that it would be inappropriate to include it in the findings. This research was to be about the participants' and families' experiences, not my own. However, I had coded 952 nodes relating to the researcher's process and experiences, and to ignore such a clear theme emerging from the data felt inappropriate. My experience and involvement was a finding, a finding I had not considered until I began writing about the end of the participants' lives, and realised that doing so required me to relive my own grief and face the multiple-layered journey I had travelled alongside them.

Working in palliative care makes a profound impact, and we ignore our own process at our peril (Kuhl, 2006). Conducting ethnographic research meant that I needed to allot a significant amount of time to being in a reciprocal relationship with the participants. This provided me with a luxury of time not afforded to health professionals working in this area. On the other hand, the intense level of engagement and reciprocity required during the fieldwork meant that it was difficult at times to separate myself from the work. I was required to participate, and the distancing devices professionals might use were, therefore, less at my disposal. Nor did I have colleagues who were in quite the same position as I was.

One of the nodes, “researcher’s role”, encompassed all the roles I had performed throughout the research process. These included: home visitor, support person, interpreter, information gatherer and disseminator, cultural consultant, liaison person, home carer, transport provider, food provider, family support person, health system navigator, counsellor, advocate, social worker, sounding board, comforter, hospital visitor, whanau member, observer, and researcher.

As I examined and compared the data, I became aware that my process as a researcher was indeed a parallel process to that of the participants. As they neared death, I neared the end of my relationship with them and their family. As they learnt about their cancer, so did I. As they became enculturated into the hospital system, my knowledge of the system also grew; as they expressed more grief, loss, and distress, I also experienced grief; as they conducted their life reviews, some of my own unresolved issues surfaced; as they suffered in agony with debilitating symptoms, I also experienced my own helplessness and vicarious traumatisation at witnessing their symptoms and distress; and as they pondered the meaning of life and considered the role of religion and/or spirituality at death, I also asked myself some of those same questions. As they let go of life, I let go of my relationship to them as research participants, and as people who had played a major role in my learning process. As the families grieved, I grieved also. As the families moved on with their lives, I moved on with the research process.

As I planned the fieldwork, I had never expected to be invited to be present as each of the participants neared death, but I was invited to do so in every single case. It may be that the

participants and participating family members reach out to those who have been part of their journey, people they have grown to trust. I was one of the few people who maintained continuity with the participants throughout their journeys, and the only consistent person they saw on a weekly basis. My relationship with the participants began at a crucial time in their lives and the conversations we had were deep and meaningful; there was little time for trivial chatter in their lives. I began my fieldwork in February 2005 and my journey with seven of the participants ended in early 2007, my journey with Billy ended in late 2008.

Each and every one of the people who took part in the study has been my teacher, my guide, and as I have helped them negotiate the unique paths of their journeys with cancer, they have assisted me in understanding the meaning and purpose of life and the reason for doing my PhD. The grief I feel is not overwhelming, it comes from a deep sadness for the losses that these people have experienced. It comes, I believe from a deep sense of compassion for them and their families. It comes from realising the frail and temporary nature of life. It comes from the loss of their hopes and dreams, for the loss of their battle with this disease, which they faced so bravely. I feel the profound loss of their companionship.

8.11 Conclusion

In this chapter, I have explored the eight participants' last days or hours in order to understand individuals' and their families' awareness of the ill participants' transition to late-stage cancer and end of life. By looking back to data recorded one month prior to the participant's death, I found that only three of the eight participants were prepared for death to come. It was interesting to note that these three had previous experiences of illness and

had similar personality traits. I have analysed this further in Chapter Nine, the following discussion chapter.

The context in which decisions are made about end-of-life care has now been explored and a number of issues have arisen from this discussion. Not all families were aware that their family member was dying; therefore, they did not all have conversations about where the person and his or her family wanted to be at the end of life. This can be partly attributed to the difficulties inherent in diagnosing dying, and the family's lack of access to clear and concise information. The families that were aware that their loved one was dying did have conversations about where they wanted to be at the time of death. Out of these six families, four decided to take their family member home, but only two were able to do so as the other two participants deteriorated suddenly and died in hospital. Although many families knew that their family member was dying, many still thought they would have more time with their loved one than they did.

From my analysis, I also found that there were two points in the participants' journeys where they were given prognoses about their life and death expectancy. These were at initial diagnosis and during late-stage cancer as they approached death. Three participants did not receive a prognosis at the point of diagnosis, and five did. Of these five participants, four were given optimistic timelines, in that they did not live as long as had been predicted. One was given a pessimistic prognosis and outlived this prediction. Seven of the eight participants were given later prognoses as their health declined, and again these estimates tended to be incorrect. They also tended to be on the more optimistic side.

As the participants' end of life was discussed, the themes woven through it were death with dignity, the good death, home aids and support, task-focused systems, where to die, and spirituality. Six of the seven participants said they wanted to die at home; three of them achieved this goal. Out of these three deaths, Elisabeth's was referred to by those present as a good death, peaceful, painless, and comfortable. Helen's was not referred to as a good death; she was distressed, in pain, and uncomfortable. Alice's death is an unknown quantity, she may have been peaceful and died in her sleep, or she may have been in pain and distressed as she had been in the 48 hours prior to her death..

Of the three participants who died in hospital, two, Daniel and Joan, were relatively pain free. The third participant, Jack, continued to experience breakthrough pain until he died. Of these three deaths, Joan's was referred to by those present as a good death, as was Daniel's. Jack's death was distressing at times for his family who watched him continue to struggle until his last breath. They did not refer to his death as a good death. Family members who were present with Tom when he died in the hospice referred to his death as a good death, as he was free of pain and peaceful. Billy's death could be classed as a good death as he achieved what he had worked so hard for, a conscious death so he could pray. The primary ingredients in achieving a good death, according to those present, therefore, were no pain or distressing symptoms, no outward sign of distress, no outward sign of struggle, and dying the way the individual wanted to.

I have come to the last of the findings chapters in this thesis. Although I have thanked everyone involved in this research at the beginning of this thesis, I feel it is appropriate to

acknowledge them again at the end of this chapter. I want to thank each and every one of the research participants, those who were ill and died, and all the family members who so graciously allowed me to part of their experience. I will remain forever grateful.

Chapter Nine

Discussion and Implications

A humane care system is one that people can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices. It honors and protects those who are dying. (Field & Cassell, 1997, p. 1)

9.1 Introduction

As I walked alongside the participants after their referral to the community palliative care team, I learnt about each of their stories from diagnosis to the end of life. I recorded each journey in chronological fashion in the form of field-notes, paying particular attention to the multiple layers of experiences, the places where the experiences occurred, the unique cultural identity of each participant, and his or her familial and socio-cultural context. The resulting product, the data, consisted of approximately 380 transcripts which were managed using the computer software programme NVivo 7. The major themes that arose from the process of grounded analysis provided the direction for each of the findings chapters, Chapters Five to Eight. Chapters Five to Seven concerned the participants' stories of diagnosis, their cultural identities within their home environments, their enculturation into the health system, and an analysis of two primary places they occupied. Through the process of analysis in writing of these chapters, the core category of "time and place" emerged. Chapter Eight, the last of the findings chapters, concerned another core category that developed over the course of data analysis, the participants' and their families' awareness of, and preparedness for death. These two core categories were interlinked as the participants' need to be prepared for death occurred at a certain point and time in their

journeys. They were, however, made aware earlier in their journeys of the need to accept their diagnosis as this would contribute to their preparedness for the end of life, as well as to decisions about how to live until that time came.

My journey with each participant began in the one place, their home. Increasingly, however, my contact with the participants occurred in health settings. The two settings where I spent the majority of my time with the participants were the chemotherapy suite and the oncology ward. Throughout the journey, I considered each participant's cultural identity and the role it played in their engagement with palliative care systems. This focus inevitably led me to consider the influence of context on their cultural identity. Prior to the discussion of these core categories and the theme of cultural identity, I will provide a review of the major themes which were discussed in each chapter.

After reviewing the major themes and the development of the core categories, I will recap the journeys taken by the participants and discuss a visual map I developed to further explicate their process through palliative care (see Diagram 5, The Roadmap, p.301). In particular, I will consider the intervention-focused approach and the palliative care approach and the different levels of preparedness that arose for the research participants depending on the level of intervention they chose. I will then consider some of the major issues that have arisen from this research in relation to the *New Zealand Palliative Care Strategy* (MOH, 2001). These issues include: timing of referral to palliative care; appropriate access to home support aids; the need for a timely and coordinated response to requests for home support; the role of the environment at the end of life; the uncertainty of

prognosis; difficulties in diagnosing dying; care coordination; and gaps in the services currently provided. In considering each of these issues, I will also discuss implications for practice. I will then reflect on the use of the ethnographic research methodology paying particular attention to the personal impact of this research paradigm. Finally, I will consider some suggestions for future research that have arisen during this research project.

9.2 Major Themes: Chapters Five to Eight

The area of enquiry identified in the first research aim: *to understand how individuals and families make meaning from the experience of being referred to palliative care services*, and explored in Chapter Five, concerned participants' awareness of their diagnosis. In the process of analysing the eight participants' narratives of diagnosis, a multitude of issues were raised and discussed. These included uncertainty of diagnosis; drawn out processes of diagnosis; loss of enjoyment of life; negotiating the gatekeeping systems to gain access to specialist care; relief and reassurance at the point of diagnosis; immediate reaction at diagnosis; and loss, grief, hope, power, and love. Hope was one of the major themes that became apparent in the process of analysing the stories and became dominant throughout the chapter. Hope was often gained through discussing options for interventions that would slow down the progression of the disease. In the majority of cases, there was little attention given to considering the need to be prepared for death at this stage.

Retelling their stories provided participants with a way of making meaning from this part of their journey. They were able to voice their fear, anger, grief, and regrets, and to focus on the journey from that point onward. I explored whether participants knew that they were

being referred to the community palliative care team because their diagnosis was terminal, and what this meant to each of them. Each of the participants had a unique story to tell, a story that told me who they were and allowed me to see them as people with “rich textured lives”. They each spoke about the diagnosis as a life-changing episode which prompted a life review and the reprioritisation of activities. This reprioritisation resulted in an adjustment of their engagement with certain parts of their wider macrosystem. For example, many of the participants stopped work and many also withdrew from social activities and clubs they had belonged to. After diagnosis, each participant began to consider information about their treatment options, and seven of the eight participants decided to have chemotherapy, radiation, or surgical treatment for their cancer. The initial discussions participants had with their health specialists provided ample exposure of therapeutic narratives and therapeutic housekeeping, which actively diverted their attention away from acknowledging endings.

The second component of the first research aim, explored in Chapter Five, was to find out how participants understood their referral to the community palliative care team, and what this meant to them. What I found was that there was little focus on this referral for the majority of participants who tended to focus on treatment, not on palliative care. The contributing factor was that the majority of the research participants were expected to live for some time, and were not, therefore, close to death, the time when they would most need support from the community palliative care team. They had not been told that they were moving towards death. At this stage in their journey, the participants spoke of the palliative care team as providing support, and they spoke of their oncologists as providing hope. This

engagement with the health system led to the reprioritisation of activities which made up the participants' macrosystem. This was discussed further in Chapter Six.

As noted earlier, my journey with the participants began in their homes and it was through an exploration of their homes, as described in Chapter Six (see section 6.2), that I developed a deeper, culturally-bound understanding of each participant's unique identity. I provided a basic description of the context, appearance, and contents of the eight participants' homes. I explored the meaning of the places participants occupied in their homes and considered various constructs, such as gender and geographical fantasy, to explore the participants' changing relationship with their environment. As I developed an interpersonal relationship with the participants, I began to understand the places they had occupied throughout their lives, and the meanings they attributed to the reduction in the number of places they now occupied. I discovered during the analysis that there was a subtle shift in the existential meanings attached to the performing of certain roles within the home environment. The participants fulfilled certain roles or occupied certain places within their homes, and these places and roles held deep symbolic meaning for them. Being able to achieve small tasks around the house on a daily basis gave their lives purpose and meaning. I also learnt about their lives prior to diagnosis and their journey from the social category of "active employed member of society" to the social category of "person living with dying". At a time when the participants ability to physically inhabit the material world was becoming restricted, they found another way of stepping outside the four walls that surrounded them, that of reflective and projective geographical fantasy (Rowles, 1978).

Through my continued involvement, I learnt about the participants' relationships with other family members and their involvement in the health system.

In exploring the participants' involvement with the health system, I considered a variety of hospital departments, including the hospital car park, accident and emergency department, oncology department, chemotherapy suite, and hospital wards. I also considered the role of support groups and their impact on the participants who attended them regularly. I explored the invisible and visible cultural markers that identify people with cancer and their affiliation with places and people who reaffirmed this new identity. The primary focus of this chapter was the enculturation of the participants into the health system, and the transformation of identity that occurred as a result.

I drew heavily on the work of ethnographer Miles Richardson (2003), in Chapter Seven, in an attempt to explore two significant places that the participants occupied: the chemotherapy suite and the oncology ward. The final result of this analysis was a contrast between two images: the chemotherapy suite as the place where disease was being tamed, and where there is a triumph of medicalisation over death, and the oncology ward with its image of death. The existential meanings of the two places were profoundly different and held quite divergent implications for the participants who spent time in them. Participants who spoke about fighting the cancer, who were determined to have as much treatment as possible, often neglected the need to consider death and dying. It was noted that as they transitioned toward death and came to occupy the oncology ward, there was also a

difference in level of social interaction. Participants tended to turn inwards towards family and close friends in the final stage of their journeys.

Having explored the places that participants occupied during their journey through palliative care, and their identity as people living with cancer, in Chapter Eight, I then turned my attention to the final part of the journey within which their identity was once more transformed from being “people living with cancer”, to “people dying of cancer”.

Chapter Eight explored the experiences of the eight participants and the 83 family members who were involved in this research as it considered their journeys. The chapter began with the major health crisis experienced by each of the participants, a crisis that marked their transition to late-stage cancer. Each of the participants sought help from a health professional. There was a change in place associated with this transition to active dying. One participant was admitted to the hospice, one was admitted to a specialist palliative care unit, and the remaining six all attended the public hospital accident and emergency department, where one was discharged home and five were admitted to hospital. I then explored the eight participants’ last days or hours in order to understand individuals’ and their families’ and awareness of the ill participants’ transition through dying to death.

What I found was that not all families were aware that their ill family member was dying. Those who were aware did not all talk about where the dying person wanted to be as death was approaching, they did not all do the things they wanted to do prior to their loved one’s death. Many family members still thought they would have more time with their dying

family member. I also found, in answer to my research aim, that cultural expression and cultural needs appeared to be more significant at the end of life than at any other part in the journey. This is discussed further in section 9.5. I also explored the themes of prognosis, awareness of approaching death, and preparedness for death. Preparedness for death became one of the core categories as I began to realise that this theme was evident in varying degrees from the beginning until the end of the participants' journeys. I recounted the death experiences of each of the participants and explored two other themes that had arisen from the data analysis: whether each death could be classed as a "good death" and a "death with dignity". I also included another theme that had emerged: "the researcher's experience".

By considering the participants' lives one month prior to their deaths, I found that only three of the eight participants were prepared for death at this stage. This finding alerted me to significant differences between the journeys of these three participants and those of the remaining five. This is explored further in section 9.4 and has contributed significantly to the development of The Roadmap (see diagram 5, p.301). Another issue that arose from this chapter, being uncertain of prognosis, is discussed further in section 9.5. Six of the eight participants wanted to die at home. Three died at home, one died in the hospice, three died in hospital, and one died in a palliative care unit. Not all the participants felt that they were dying with dignity as they began to experience the loss of bodily functions and uncontrolled pain. The primary ingredients that were identified as contributing towards what the families termed "a good death" were no pain or distressing symptoms, no outward sign of distress, and no outward sign of struggle.

The findings chapters, Chapters Five to Eight, were presented in chronological order, from diagnosis to death. They mapped the journeys undertaken by the eight participants, reflecting the multi-contextual nature of each participant's experience. The individuals' and families' unique cultural identities were explored in the chapters and highlighted through the use of field-note extracts and verbatim quotes.

9.3 Developing the Core Categories

In this section, I will discuss the development of the two core categories: "time and place", and "preparedness for death". Firstly, in looking at the core category of time and place, I reconsider the development of each of the findings chapters using grounded analysis and how each chapter contributes towards an understanding of this core category. I then draw on ecological systems theory presented in Chapter Three to locate this core category within this theoretical framework. The second core category is discussed with the use of a visual representation, The Roadmap (diagram 5, p.301) and considers the paths each participant took on his or her journey. This leads to a discussion of Stroebe and Schut's (2001) dual process model, and the application of this theory to particular people and situations. Following on from this, the three paths participants took, and their preparedness for death, are considered and discussed.

9.3.1 Time and place

The ethnographic data collection methods assisted me in gathering data from many spheres of each participant's life, whilst also taking into account the locations in which the experiences occurred, as well as the location in which the story was told. The grounded

theory analysis of this data resulted in numerous codes relating to specific issues. For example, in Chapter Five, I explored participants' homes and their occupation of this place, I developed a sense of their cultural identities, who they were as unique individuals. I explored how their diagnosis with a life-threatening illness impacted on their occupation of their home environment. Drawing on an ecological systems perspective, I considered the many systems they were involved in and the changes in their interactions within these systems after diagnosis. The codes that emerged from the analysis were hope, loss, grief, power, and love. Through constant comparison, I began to see a pattern of how these codes were located within the stories of diagnosis. In comparing the themes underlying the stories of diagnosis, I came to realise that there were sub-categories of stories and these sub-categories related to the process of diagnosis. The theoretical categories that emerged related to the participants' awareness of the terminal nature of their diagnosis. This analysis was presented using narrative analysis in this one chapter. This was done because the story of diagnosis was the only retrospective data collected and it seemed sensible to employ narrative methods to the analysis. What I did not consider at the time of initially writing Chapter Five, was that these stories were located within a specific time period and the diagnoses occurred within certain places.

I then moved on to the initial writing of Chapter Six. The codes that emerged from the grounded theory analysis were identity, referral, new places, identification, and enculturation. After the comparative process of analysis, the theoretical categories that emerged were: rite of passage, liminal spaces, subjective and interpersonal understandings of place, gender, geographical fantasies, and cultural markers. Although I discussed time

and place in relation to these theoretical categories, I still did not regard it as a core category.

Continuing on with the participants' journeys, many of them became involved in treatment and were increasingly admitted to hospital and attended oncology clinic appointments. As I began to talk about the emerging themes with my supervisors, they asked me if I was aware that I had often spoken about time and place, and about how the participants' experiences and cultural identities could not be separated from the context of place. Further discussion highlighted the context specific nature of the participants' experiences, they happened to certain people in certain places and at certain times. It was as if someone had turned on a light; I had been writing about time and place since the beginning of the thesis and yet I had not identified this as a core category. Returning once more to the grounded analysis, I identified the theoretical concept of embodied spaces, the conjunction of the physical being and place, and the interactions between the two. Through conducting a literature search relating to time and place, I discovered Low and Zuniga's (2003) edited book *The Anthropology of Space and Place*, and within this, an article by Richardson (2003) which provided a framework for the analysis of behaviour in and of different places. This literature was used to structure Chapter Seven. In this chapter, the framework and analysis was drawn on to highlight behaviour that was "in" or "of" the environment and the extent to which the ill participants conformed to the cultural norms of the environment that they relied on for their very existence.

The core category of “place” had now emerged and continued to be an important contribution to the initial writing of Chapter Eight. This chapter concerned the end of the participants’ journeys as they were approaching death. The themes to emerge from the grounded analysis were: transition to late-stage cancer, awareness of impending death, diagnosing dying, information, preparedness for dying, prognosis, a good death, place of death, and family culture. At this time, the participants’ levels of preparedness for death throughout their journey became more apparent. “Preparedness for death” became the other core category, as I came to understand how this overarching theme had been present in the data since my first meeting with the participants. I also began to see how the path that each participant had taken had either enhanced, delayed, or limited his or her acceptance of a terminal diagnosis. This core category is discussed in further detail in section 9.4. It was also at this stage in the participants’ journeys that family members became more involved in the research. Due to their deteriorating health, the participants were often, but not always, sedated or unconscious as death approached. Up until this point, I had been primarily involved with the participants, their primary carers, and the people they saw most often. As death approached, families arrived and congregated at the bedsides of the dying participants. With the arrival of their families, participants were immersed back into their own cultural realm.

9.3.2 Ecological systems theory: Time and place

The ecological systems perspective provides a framework for locating participants within varying systems they were involved in from the beginning, when they were diagnosed, until the end of their journey, when they died. The chronosystem provides a life course

perspective by which to view the transitions throughout the participants' journeys. Mapping this journey on paper, I could clearly see how the sociocultural context of participants' lives had diminished over time as they become less involved in macrosystems which supported their cultural identity. Their identity transformed as they began to engage in a different macrosystem, that of the health system, and disengage from their previous macrosystems of work, groups, and various activities. Within this new macrosystem, they were identified by cultural markers as "people living with cancer". As participants approached death, their relationship with the health system moved into the background and their relationship with their original macrosystem was reinstated by the presence of family members whose cultural identity had not undergone the same transformation. Although many of their interactions still occurred within the broader context of the health system, there was also a sense that because they were dying, the health system, with its offer of hope, had somehow failed them. There was no longer anything that doctors could offer that would extend their lives further. Time was a precious commodity they no longer had. Although home was identified as the ideal place to be at the time of death, symptom management combined with a lack of ability to accurately predict imminent death often led to people dying in hospital or other care facilities. Relocation of the dying person to hospital or hospice was discussed in Chapter Eight; an issue that was highlighted was the absence or unsuitability of places for families to gather. Use of the ecological systems theory firmly locates the participants' journeys within a construct that takes into account the core category of time and place. The other core category of preparedness for death will now be explored in further detail.

9.3.3 Intervention, palliative care, and preparedness for death

The Roadmap (see Diagram 5 below) provides a visual representation of the participants' journeys from diagnosis to the end of life.

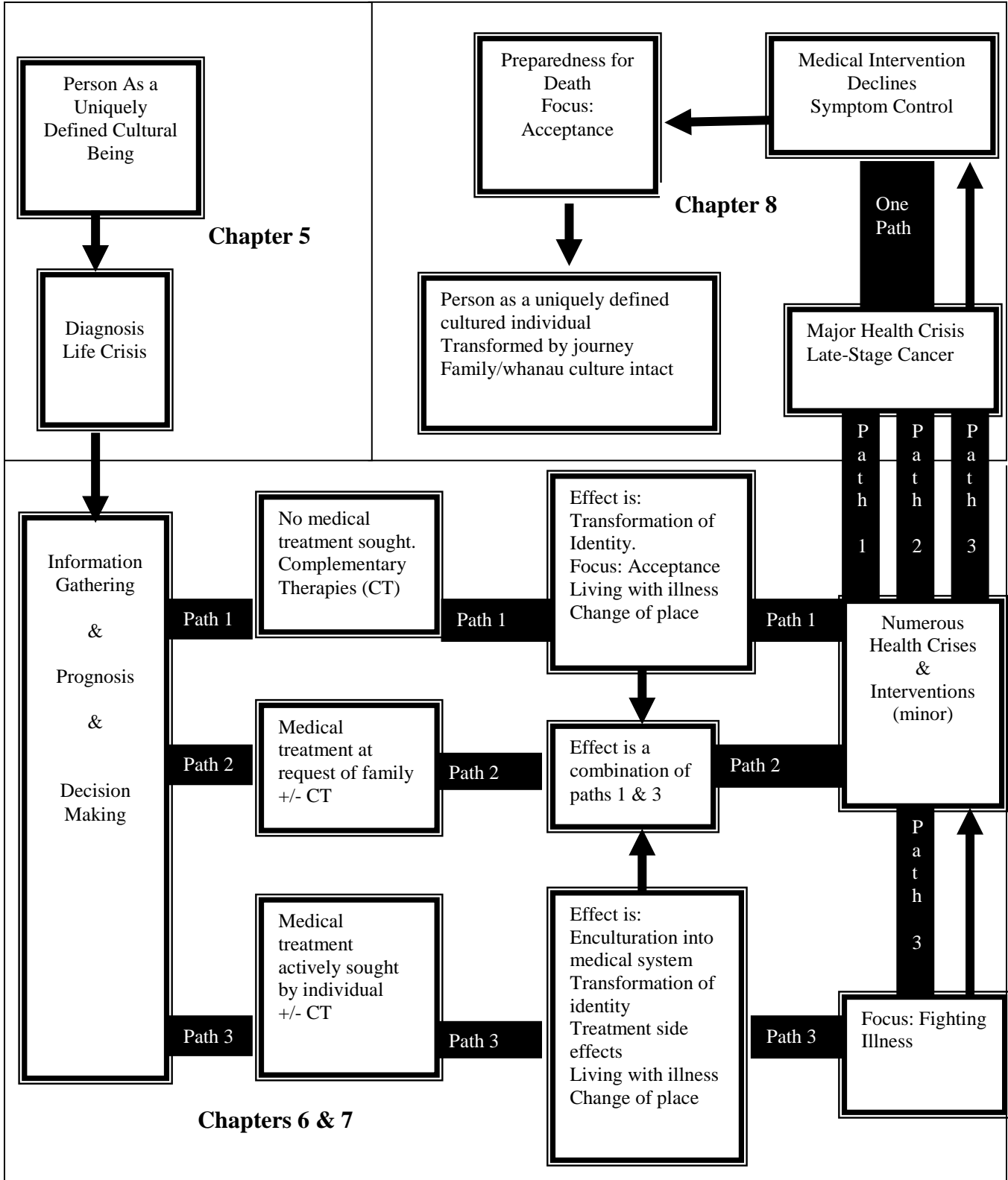


Diagram 5: The Roadmap.

The diagram is divided into four sections, each section corresponds to a particular chapter in the thesis. The differences and similarities of each participant's journey is explored throughout the chapters and mapped out in this diagram. In order to visually represent the eight journeys, a certain amount of detail has inevitably been lost. In particular, the number of smaller health crises experienced by each participant varied and are not individually represented here. A health crisis is defined by the need for medical intervention, such as admission to hospital, attendance at the accident and emergency department, or the need for an urgent GP visit at home. The minimum number of health crises for any one individual was three and the maximum was 15. These were health crises that required a level of intervention.

Diagram 5 shows the different pathways each participant took, as indicated by the boxes. The diagram is merely a representation of the participants' journeys; it does not attempt to contain the minute detail of each participant's journey. The paths one to three represent the different paths taken by the research participants. These three paths merge as the participant approaches death. Chapters relating to each part of the diagram are indicated by a fine line outlining the appropriate sections. Medical treatment is defined as including chemotherapy, radiation, or surgery; CT means complementary therapies.

Drawing on the ecological framework, participants' lives and deaths have been located within their social context as people who had occupations, families, social networks, religious networks, hobbies, and friends; lives they had carefully or haphazardly

constructed. Each participant was a unique individual with a unique cultural identity, who was given a terminal diagnosis of cancer and embarked upon his or her own journey by first gathering information. All were referred to the oncology department at a public hospital where they underwent scans and blood tests, and were referred to the community palliative care team. After more definite diagnosis, they were all offered treatment plans. At this stage, there were three different paths that the participants took. In reviewing these paths, I will apply Stroebe and Schut's (2001) integrated dual process model which I discussed in Chapter Three (see section 3.9), in conjunction with the ecological framework (discussed in section 3.6). Doing so allows the environmental factors in the process of loss and grief to be considered.

9.3.4 Applying Stroebe and Schut's dual process model

Billy took path one (see Diagram 5) and decided to use only complementary therapies. He accepted that he would eventually die and declined all chemotherapy and radiation treatment. This choice resulted in Billy remaining fully involved in his original macrosystems which contributed to his cultural identity. Applying Stroebe and Schut's model to Billy's journey, he could be seen as adopting a loss-orientation after his diagnosis as he focused on the grief of his diagnosis and the losses that would occur in his life as his health deteriorated. He engaged in complementary therapies which, in theory, can be regarded as engaging in restoration-oriented behaviour. He drew on his faith in an attempt to develop positive meaning construction from this situation but this was not solidified for him until the last few months of his life. His oscillation between these meaning states led to the development of his coping strategies. One of the coping strategies Billy employed, once

he realised that he would not be able to live much longer with his illness, was to give away his possessions. Billy had been experiencing a high level of distress about his life and his diagnosis, and as his body became weaker, he often spoke about wanting to die. Giving away his possessions helped Billy to deal openly with his feelings of loss associated with his previous life and approaching death. In this way, he engaged in what Lindemann (1944) refers to as “grief work” and what Worden calls “accepting the reality of the loss” (Worden, 2002, p. 27) and working through the “pain of grief” (Worden, 2002, p. 30). As Billy gave away his possessions, he talked about what they meant to him and why he had chosen to give things to certain people. Billy also moved out of his home and into a private care facility, this major shift in environment aided his process of “letting go”. Billy reframed this letting go of material possessions as being a step towards his preparation for leaving his body. In this way, his loss-oriented behaviour resulted in the development of positive adaptive responses to grief. Without his material possessions, he felt that he was free to leave what he referred to as “the material world”.

Alice and Joan took path two (see Diagram 5) and indicated that they accepted they would die but had undertaken treatment because family members wanted them to. They both stopped treatment prior to its completion and refused any further treatment. I have applied Stroebe and Schut’s dual process model to Alice’s journey to demonstrate the application of loss-oriented behaviour, and positive meaning construction. When I first met Alice, she was engaged in a process of sorting through her personal belongings so that she could leave each of her children a memory box. Alice enjoyed thinking about her sons’ lives and the memories she had of them growing up. Making memory boxes for them was Alice’s way

of acknowledging the loss she felt about leaving her children when she died. Alice developed an activity centre in her lounge at home, and she positioned her chair in the midst of the paraphernalia that she used for each of her projects. Being in this activity space gave Alice a sense of purpose. She had things to do even though many of those things were about saying goodbye. She wrote goodbye letters to all of her family members and friends, she made chocolates and cards to thank people for helping with her wedding, and she planned her own funeral. Alice was very distressed about her impending death and often spoke of her funeral and of losses in her life. This would fit with Stroebe and Schut's conceptualisation of loss-orientation. However, although Alice was grieving, she was smiling as she recalled many happy times throughout her children's lives. Drawing on the meaning states introduced into the new dual process model by Stroebe and Schut (2001), as discussed in Chapter Three (see section 3.9), this could be understood as positive meaning construction. Being able to acknowledge her loss, and being able to feel positive about an action she was taking to cope with the loss, resulted in a positive adaptive response to grief. Application of the integrated model suggests that if Alice had acknowledged the loss she felt by engaging in negative meaning states, and ruminating about the loss of her life, she would most likely experience maladaptive coping or depression.

Jack, Daniel, Elisabeth, Helen, and Tom all took path three (see The Roadmap, diagram 5, p.301) and made a commitment to fight their cancer. They all wanted as much treatment as possible throughout their journey. The more involved participants were in the macro health system, the greater the influence of this system on their cultural identities. I will also apply Stroebe and Schut's integrated dual process model to Helen's case to demonstrate the

application of restoration-oriented coping, and positive meaning construction after diagnosis.

Helen immediately engaged in a restoration-oriented coping strategy when she was diagnosed with a terminal illness. She requested immediate surgery to remove the primary cancer. She also engaged in positive meaning construction by explaining that with surgery and treatment she felt sure she would live many more years. She returned to work and was determined to live every day as fully as possible, for as long as possible. Application of the dual process model suggests that if Helen had engaged in restoration-oriented/negative meaning construction, she would have had the surgery but would also have dwelt extensively on the chance that she would still die as a result of the cancer. In Helen's case, maintaining a positive restoration focus was done by engaging in as much treatment as possible, and focusing on living as long as possible. Helen explained that if she began to think about death and dying, she would become very depressed. Therefore, she did not spend time preparing herself for death and was distressed when she was told that she was dying.

The dual process model with its integrated meaning states suggests a process of oscillation between loss and restoration orientations and the two different pathways of "positive meaning construction" and "negative meaning construction" (Stroebe & Schut, 2001, p. 397). Stroebe and Schut argue that oscillation between these orientations and meaning states leads to adaptive coping. In the three cases where I have applied the dual process model, different levels of oscillation can be seen. Billy and Alice spent more time in loss-

orientation with a focus on developing positive meaning from their deaths. Helen spent more time in restoration-orientation and developed positive meaning by living as long as possible. The ecological perspective expands the dual process model and leads us to take into consideration such matters as prior relationships with death, messages about prognosis, and resources for adequate and timely care in the transition towards death. The journey each participant was on occurred within a particular environmental and cultural milieu which changed over time as the participant's health deteriorated. In the following section, I will consider the different paths the participants took, the level of intervention they engaged in, and their preparedness for death.

9.3.5 Different paths: Intervention and preparedness

Participants who took paths one and two (see Diagram 5) were clearly transformed by the experience of being diagnosed with a terminal illness. They withdrew from life in many ways, engaging in little social activity outside of their homes. They reprioritised their activities and gave up working completely. They engaged in a life review and began organising their funerals and drew up new wills. They also put more energy into quality time with family members. Additionally, those on path two experienced a level of enculturation into the health system as they engaged in treatment and experienced side effects from this. They, therefore, experienced a measure of both a level of enculturation and a level of acceptance. Those on paths one and two all experienced health crises for which they had medical intervention and from this point on their paths again merged with those who had originally taken path three.

Participants on path three experienced a loss of identity as they became fully enculturated into the medical system. The components of their macrosystem, which had previously contributed to their understanding of their cultural identity, were, to a point, replaced by the macro components of the health system, thereby resulting in a change of identity. In considering Stroebe and Schut's model, these participants could be seen as engaging in problem-focused coping mechanisms, as they embraced the treatments offered to them in an attempt to improve the situation they were facing. They focused on fighting the illness, and all spoke of a future. They held onto the medical hope that was offered by continually engaging in treatment. From a theoretical perspective, these participants could be regarded as engaging primarily in restoration-oriented attempts at coping, by continually engaging in therapeutic intervention. The issue of intervention has been highlighted in the *New Zealand Palliative Care Strategy* in the following two quotes:

With 39 percent of cancer deaths occurring in public hospitals, the palliative approach perhaps appropriate to the dying person's care be lacking in the hospital environment. Clinical hospitals have a strong curative, intervention-focused culture; institutional settings for the care of older people and those with degenerative conditions offer scanty provision of palliative care. (MOH, 2001, Appendix 5: Issue 1, p. 45)

The National Health Committee noted that too frequently people continue to receive inappropriate levels of intervention when they would have been better served by a palliative approach. The normality of death as a process in life's cycle is in danger of becoming 'medicalised'. (Smith as cited in MOH, 2001, p. 43)

The National Health Committee is also cited as noting that research has identified that doctors tend to overestimate a patient's survival rate, and that health professionals often consider palliative care appropriate only when a person is viewed as imminently dying

(MOH, 2001). This issue was discussed in relation to the uncertainty of prognosis (see Chapter Eight, section 8.7).

In relation to the five participants on path three, who were not prepared for death, each participant was clearly focused on further intervention and not one believed he or she was imminently dying. The participants did not receive timely palliative care and were still considering treatment at the point of their major health crises, which, along with the participants on paths two and three, moved all participants into late-stage cancer.

At this stage in each participant's journey, the level of medical intervention became more evenly balanced, with all participants receiving symptom control and pain management as required. As the participants neared death, family members became more involved in the health systems and the dying participants were all encouraged to accept that death was approaching. As participants attempted to let go of their focus on medical life-extending interventions, each began to face death in different ways. Each participant was treated as a unique individual with his or her own needs, own family, and own dying process. This process was spearheaded by family members who had not been enculturated into the health system in the same way. This issue was discussed in relation to systems theory in Chapter Eight (see section 8.9).

At the time of death, three participants were prepared for death, they were those who had taken paths one and two, as shown in Diagram 5. Five participants were not prepared for death, they had taken path three. They had believed they would have more time to live.

They had not done the things they wanted to do or said all the things they wanted to say. They had not accepted that they were in fact dying, and were, on many levels, still very involved in living. Although we can clearly see that some participants took one path and some another, this does not tell us *why* they chose particular paths. This question will now be explored in more detail.

9.3.6 Why that path?

The use of therapeutic narratives, discussed in Chapter Five (see section 5.3.1), tended to keep participants focused on current treatment and possible future treatments rather than encouraging them to talk about life endings. As a result, they believed that their oncologists still had “something up their sleeves” that they would be able to “pull out” at the last moment and extend life once again. Of the five participants who were not prepared for the end of life, four spoke about “fighting” their disease, and made comments such as:

Tom: “I’m a good staunch kiwi bloke, and I’m not about to give up.”

Helen: “I’m as tough as an ox and fierce as a grizzly bear.”

Jack: “You have to tighten your bootstraps and get on with it.”

Daniel: “If I keep eating and getting lots of fresh air, I’ll be fine.”

The other participant who was not prepared for death was Elisabeth who said repeatedly:

“My chest X-ray is good, I’m eating well, and I’m going to have some more treatment later on.”

By contrast, the comments made by the three participants who were prepared for death were:

Joan: “We all have to die sometime, and I’m not afraid.”

Alice: “I’m not going to live, there is no cure, so I don’t want to pretend.”

Billy: “I want to be prepared for death, so I need to face the reality that I’m not going to live.”

These comments reflect a component of each participant’s identity (as discussed in Chapters Five and Six), and indicate a different reaction to diagnosis and prognosis (see Chapter Eight, section 8.7, for discussion of the impact of prognosis on these three participants). In searching for an explanation of why some participants chose one path and some another, I began to wonder about the similarities and differences between the groups. I considered the eight participants’ demographic features. All participants had been married at some point in their lives, and seven of the eight remained in relationships one month prior to their deaths. All had children. Financial status did not seem to play a role in their decision making nor did occupation, age, or ethnicity. For one participant, Billy, religious beliefs played a significant role in the choices he made. As his end of life became imminent, he chose to stop all intervention and prepare himself spiritually for leaving his body. The lack of a clear pattern in terms of preparedness for death with the remaining participants meant that I had to go back to the data and look for commonalities or differences between all the participants.

Two of the participants who were prepared for death, Alice and Joan, had experienced an earlier diagnosis of cancer prior to the current diagnosis; Alice five years and Joan four years before. They had both undergone surgery and although their diagnosis was considered serious, they were eventually declared to be “in remission”. The third participant who was prepared, Billy, had experienced a life-threatening illness many years

prior to his current diagnosis. It is possible that previous experiences with a life-threatening illness do, in some way, prepare people for further life-threatening events. This group of participants seemed more open and accepting of their diagnosis and often referred to the extra time they had been given as “a gift”. As Alice explained one day, “*You can only cheat death once.*” However, it was not only the experience of a previous life-threatening illness that may have helped these participants prepare for death, but their approach to their initial diagnosis.

Each of the three participants in this group thought about the possibility of dying during their first serious illness, and this appears to have contributed to their acceptance of, and preparedness for death when they were diagnosed with another life-threatening illness. It is difficult to establish whether another variable may have been contributing to these three participants’ acceptance of their death but it is most likely that this is so. This variable may also account for the difference between the responses of the three prepared participants, who had a previous diagnosis, and the three unprepared participants, who had also been previously diagnosed with a serious illness.

Three of the unprepared participants said they had not considered their mortality the previous time they were diagnosed with a serious illness. They focused on surgery and treatment, and curing their illness. The remaining two unprepared participants had not previously experienced any serious ill health during their lives.

There are, therefore, two groups of participants who had all experienced previous serious ill health, the prepared group of three and the unprepared group of three. The prepared group had all understood the seriousness of their first life-threatening illness and had thought about death at that time. The unprepared group did not openly acknowledge the seriousness of their first illness, and did not talk about any previous awareness of death. Having now reached this possible explanation for the difference between the two groups, I began to think about the three prepared participants' personalities and came to another realisation.

The three prepared participants all spoke of feeling a sense of abandonment at some point in their lives, of feeling alone, vulnerable, and unprotected. They had carried the emotional pain of these experiences throughout their lives. When they began to review their lives after being given a terminal diagnosis, they uncovered this pain and began to talk about it. Kuhl (2002, p. 214) states: "A sense of belonging becomes heightened for many who know they have a terminal illness." It becomes heightened because of the process that occurs after diagnosis. The participants all began a process of evaluating their lives and reprioritising the way they had lived. All of them said that it was after diagnosis they realised that the people in their lives were the most important thing, not money, not work, not possessions—people, primarily family members and close friends. The three prepared participants all took time to say goodbye to those they loved and to deal with any unresolved issues.

9.3.7 Preparedness for death: Discussion

The theme "preparedness for death" has become prominent throughout the thesis. I have provided a roadmap (Diagram 5) to determine which participants reached a state of

preparedness. In the discourse surrounding end-of-life care, there is a sense that reaching the state of acceptance and preparedness for death is an “ideal” goal. However, I want to consider for a moment why this is such a focus. Throughout the fieldwork, the dominant discourse that I heard participants being confronted with was related to preparedness for death. I came to believe, as did the participants, that this was indeed the goal. Because this was talked about so often, it was recorded in my field-notes and eventually became one of the core themes in this thesis.

In conjunction with the focus on preparedness, other issues that arose in the process of data collection and reviewing the literature on death and dying were: the good death, to live until we die, conducting a life review, resolving issues, making peace, acceptance, and breaking bad news. From the identification of these issues, it seems as though we are trying to reclassify death as an opportunity for change rather than a distressing, anxiety-provoking process. Throughout this study, I have been confronted with many situations where death was not nicely packaged, it was not tidy and sanitised; it was sometimes messy and chaotic. This raises certain questions for me, such as: Are we attempting to tidy up death because we do not want to accept the “messiness” of its reality? Are we attempting to control death as a way of protecting ourselves from our own fear of it? Is the encouragement of preparedness for death an attempt to move the dying out of restoration-orientation and into loss-orientation with a positive meaning pathway?

When she was dying, one of the research participants, Helen, was told by a nurse to “calm down”. This raises further issues and questions for me. Helen clearly did not want to die,

should she not have every right to wail, scream, or protest her death if that is what she needed to do? How do we know that her process of dying was any better or any worse than that of the participants who died quietly sedated? Maybe it was more important for participants to hold onto their hope than it was for them to spend their time preparing for death.

People die suddenly every day in a multitude of ways. This raises even more questions: Were they prepared for death? Are we prepared for death now? How important is it that we should be prepared for death on a daily basis, just in case it happens? Most of us do not even consider being prepared for death. Yet when someone is given a life-limiting diagnosis, they are encouraged to work towards resolving issues, to confront the reality of their situation, and to prepare themselves for death, whilst also focusing on living until they die. Who decides that people with a diagnosed illness need to be more prepared for death than the millions who die every day without a diagnosis? How do we know that the deaths of those who are prepared are any “better” than those who were unprepared? Are we merely trying to protect the living from the reality of death, and to minimise the social impact of loss and grief? When Lindemann's (1944) manifestations of grief, discussed in Chapter Three (see section 3.7), are considered, such as preoccupation with the lost person/object, somatic distress, feelings of guilt, hostility towards others, and a breakdown in the usual patterns of functioning, it is clear that these are not feelings that people desire.

Lazarus and Folkman's (1984) theory of coping as a mediator of emotion, also discussed in Chapter Three (see sections 3.7 - 3.8), suggests that there are two responses available to the

individual who is faced with a stressor or threat. These are: problem-focused coping, which attempts to manage the problem, and emotion-focused coping, which is an attempt to regulate the emotions associated with the event. Engagement in these two coping responses leads to either a favourable resolution or an unfavourable or no resolution. Favourable resolution then results in positive emotion and the resolution of the perceived threat. Unfavourable resolution or no resolution results in distress, which leads to further reappraisal of the situation. Findings from Folkman's (1997) study indicate that caregivers' engagement in active problem-focused coping led to less negative mood, and an increase in positive mood. The increase in positive mood was attributed to a greater sense of control and mastery experienced by the caregivers. Further questions, therefore, are: Is the same situation occurring with health professionals in the end-of-life care field? Are our attempts to encourage the dying to prepare for death our way of engaging in problem-focused coping? Is this how we have learnt to maintain our positive approach and stamina so we can continue to work in this field? Are we merely attempting to control death so we can assure ourselves that everything is under control, that we have death mastered?

9.4 New Zealand Palliative Care Strategy and Practice Implications

It is time to review the vision statement of the *New Zealand Palliative Care Strategy* (MOH, 2001) that was discussed in the literature review, Chapter One (see section 1.5). There are a number of issues that have arisen throughout the thesis, which I will now consider in light of this statement: "All people who are dying and their family/whanau who could benefit from palliative care, have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way" (p. vii).

Several pertinent issues have arisen through this study. These include: the timing of referral to palliative care; equal access to home support aids; timely response to requests for assistance when a family/whanau member is dying at home; a coordinated response to the needs of the dying; the environment in which death is occurring; the provision of culturally-appropriate services; the uncertainty of prognosis; difficulties in diagnosing dying; and gaps in services, such as the provision of information. Finally, I will consider the roles that I fulfilled in the course of this research, the role of care coordinator discussed in the *Palliative Care Strategy* and the actual and ideal role and function of social work.

9.4.1 Timing of referral to palliative care

As outlined in Chapter Four (see section 4.4.1), there were two separate processes for the recruitment of participants: The initial recruitment that occurred with the support of the community palliative care team, and the second recruitment process that occurred later in the fieldwork, and was supported by the hospital-based palliative care team. In each case, issues arose pertaining to the timing of referrals to palliative care services. Although there are a substantial number of referrals made to the community palliative care team on a weekly basis, in terms of this study, very few people were considered to be suitable research participants by the specialist nurses because they were either very ill or very close to the end of life. As I was not aware of this issue prior to conducting this research, I had no idea that recruiting participants would prove to be so difficult. In response to this situation, and in an effort to recruit additional research participants, I devised an additional recruitment process. This meant reapplying for ethics approval and extending the period of time in the field. By doing this, I did receive further referrals to potential participants.

However, I was unable to use any of the data from these participants. In one case, full consent was not gained from family members, and in the third and fourth cases, the potential participants were too ill by the time the referral was made and they died within a few days.

In the process of attempting to recruit participants for this research, I found that referral to palliative care services often occurs very late in the disease process. Having confirmed this with staff at both sites, the hospital and the hospice, I would like to highlight this as an area of concern. Conversely, as discussed in Chapter Five (see sections 5.3 & 5.6) it also became apparent that when referrals to the community palliative care team occurred, while the participant was still quite well, the referral held little meaning for the participants. Participants who were still working, or quite involved in life at the point of their diagnosis and referral, saw little need for palliative care services at that stage. One of the participants was removed from the books of the referring agency for a period of time as she did not feel that there was any point in continuing contact when she did not need any support. I was referred to her when she instigated contact with the agency one year prior to her death. Referrals that were made too early meant little to the participants, who tended to be unsure what roles and tasks the community palliative care team actually fulfilled. The time period in which the community palliative care team services proved to be invaluable to the participants appeared to be approximately the last two months of life. At this stage, the service provided access to home support aids, home nursing care, a point of contact for concerns or queries relating to medication and pain relief, symptom management,

encouragement, respite care, end-of-life care, grief counselling, family support, and bereavement counselling.

9.4.2 Access to home support aids

On meeting participants, I paid particular attention to the types of support they were currently getting at home and what support aids, if any, they had. Jack and Daniel had no support aids and did not know these were available. Although they were both still active, they both had lung cancer and, at times, experienced difficulty sleeping lying flat in bed. Yet neither of them knew that they could get a bed raiser, a back board, or a recliner chair, aids that would have made them more comfortable. When I first met Elisabeth, she was using a bucket on top of a stool as a commode and was having difficulty balancing on it when she was unsteady on her feet. She also needed to hold on to the furniture to move around. Elisabeth would have benefited greatly from the use of a commode and a walking frame. Alice often slept on her couch at night when I first met her, as she found it quite difficult to lie flat and sleep. She would have benefited from the use of a recliner chair at that stage. Helen and Joan did not know anything about home support aids nor did they need any assistance when I first met them. Tom did know about some of the home support aids he was entitled to but he had a walking frame when I met him. He had requested a hospital bed, but was told they were reserved for people in the last stages of life and he was not there yet. He was sleeping on the couch in his lounge. This was ten days before he died. Billy did not know about home support aids but could have benefited from a recliner chair, as he often sat in the lounge with a heat pack on his back when he was in pain.

Although my role was that of researcher, not social worker, I felt it was necessary to inform Elisabeth's daughter that she could make contact with the community palliative care team to ask for a commode and walking frame. This encounter with Elisabeth was the first time during the research process that I felt the need to put on my professional social work "hat". I discussed becoming involved on this level with my senior supervisor at the time. She asked me a question which became my measuring stick for future involvement on this level. She asked if I would sit and write about a person dying of pneumonia or whether I would call a doctor. I replied that, obviously, I would call a doctor. She suggested that whenever I went into a new situation, I should go as a human being first and researcher second, and that it was not a blurring of boundaries to instigate social work involvement, or inform people of their rights. The only risk was if I acted as a participant's social worker.

Following that discussion, I let participants know that support aids were available by request through the community palliative care team. Three participants were eventually provided with recliner chairs in their homes and were very grateful to community palliative care team and the Cancer Society for providing these. Three also received wheelchairs and two received walking frames. Two were provided with commodes, including Elisabeth. One was provided with a hospital bed the day prior to her death at home. Another participant also received an air mattress the day prior to their death at home. Tom did not receive the hospital bed he had requested. On informing the participants that these home support aids were available, they all asked me a similar question: "Why hasn't anyone told us about them?"

One participant suggested that it would be very useful if the community palliative care team or the oncology department would provide a pamphlet with information about such things as home support aids and Cancer Society meals. This would be an excellent resource for people with a terminal illness and could also include information such as accommodation for family/whanau members from out of town, contact phone numbers, and other resources, such as the Cancer Society holiday homes.

Participants' access to home aids was variable, with some participants receiving this type of support, and some not receiving such aids in a timely fashion. The goal of equal access to home support aids, which are classed as essential services in the *New Zealand Palliative Care Strategy*, is difficult to achieve unless the people who need the resources are aware of them and know how to access them. Conducting a social work assessment at the time of referral to services, such as the community palliative care team, would also highlight these needs and provide assistance in having them met. Such an assessment would also highlight the financial needs of people who have been adversely affected financially as a result of their illness. However, at the time the *Palliative Care Strategy* was published, in 2001, only nine hospices out of the 32 New Zealand hospices provided social work services, that is only 28% of all hospices.

9.4.3 Timely responses for home assistance

In discussing the day of Helen's death in Chapter Eight (see section 8.8), I noted that her family began asking for assistance at approximately 5am. They called Helen's GP and the community palliative care team. Her GP came out to see her one-and-a-half to two hours

later, and told the family and Helen that he was unable to provide any further pain relief and that the community palliative care team would need to set up a morphine pump. The family made two phone calls to the community palliative care team and I made another. Two members of the community palliative care team arrived at 10.45am, close to six hours after the initial call. Helen had been in extreme pain and distress throughout this time. Her family had also been very distressed and felt helpless to do anything but watch her suffer. This situation raises questions about the level of support that is provided for families and the dying when they are at home.

The *Palliative Care Strategy* promotes a “community model of palliative care services” (MOH, 2001, p. 7), which means that people are encouraged to die at home surrounded by those they love as opposed to dying in a hospital. Promoting death at home as a viable option for individuals and families would require consistent responses being made to people in need. As well as promoting a community-based model of palliative care, the *Strategy* has a number of aims, one of which is to “develop a more responsive system that can support a person[’s] choice to die at home” (p. 6). After Helen’s death, her partner often questioned whether Helen would have been better off dying in hospital or the hospice, than at home. It raises a vitally important question that requires further consideration, namely, Is home the best place to die?

9.4.4 Coordinated response

In order to implement the vision of the *Palliative Care Strategy*, one requirement that is mentioned is the “provision of essential palliative care services for people who are dying

and their family/whanau (these include care co-ordination to ensure that services are coordinated and appropriate for each individual)” (MOH, 2001, p. 14). An issue that arose for Bill, who was caring for his partner Joan at home, was that Joan developed mouth ulcers and was unable to eat, drink, or talk. She was in immense pain and needed help. Her partner, Bill, was doing all he could to care for her and had asked for assistance from their family doctor and the community palliative care team. He felt that the help he had received from both sources was inadequate and did not meet his or Joan’s needs. He requested that Joan be admitted to hospital but did not receive any assistance to arrange this.

If Joan’s care had been provided in a coordinated responsive manner, based on her needs, her partner would not have felt that he had to fight the system in an attempt to get help for Joan. He felt very frustrated and upset about this encounter, and often expressed anger about this after Joan’s death. Bill was doing an admirable job caring for Joan at home, but he was reliant on support from the community palliative care team, as Joan did not have a good working relationship with her GP following the number of misdiagnoses that she felt had been made prior to her diagnosis with cancer. After her admission to hospital, Joan was treated for the mouth ulcers and received relief from this intervention. The result was that she was able to drink and eat a little and was able to have vital conversations with her family before her death 11 days later.

9.4.5 Care coordination and gaps in services

One of the methods I drew on throughout the research was to pay attention to the roles into which I was invited but resisted entering. A number of these roles were discussed in

Chapter Eight (see section 8.10). Those pertaining to gaps in services included home visitor, support person, interpreter, information gatherer and disseminator, cultural consultant, liaison person, home carer, transport provider, food provider, family support person, health system navigator, counsellor, advocate, social worker, sounding board, comforter, and hospital visitor. The *Palliative Care Strategy* (MOH, 2001) states:

Each person who is dying should be allocated a care co-ordinator at, or following, the initial assessment. The care co-ordinator is responsible for ensuring that the dying person and their family/whanau are provided with information regarding palliative care options and services, and that the family/whanau are provided with the necessary information and skills to assist in caring for their dying family member. The care co-ordinator also has responsibility for co-ordinating and ensuring access to the appropriate palliative care and other services. . . . The care co-ordinator will ensure care is appropriate to the person's needs and culture. (p. 8)

As the social work role is to link people with support systems, provide information, advocate for their clients, liaison with other services, provide counselling and psycho-social support, and coordinate support services (Christ & Sormanti, 1999; Csikai & Bass, 2000; J. Tan, personal communication, October 20, 2005), it would seem they are ideally placed to fill the role of care coordinator. Social work in the health field is provided to assist people with the psychosocial implications of illness, particularly long-term illness. However, there is a need for specialist training of social workers in end-of-life care (Callahan, 1995; Csikai & Bass, 2000; Ellershaw & Ward, 2003) in conjunction with ethics training (Manetta & Wells, 2001). During background interviews, I learnt that there is also an issue with scarcity of funding for social work practitioners in the current New Zealand health climate, resulting in very few patients having access to social work services: approximately 2000 referrals are made to the hospital oncology department per annum, and approximately 700

of the people referred will be able to see a social work practitioner (D. McMaster, personal communication, July 8, 2005).

9.5 Research methodology: Reflections

The utilisation of an ethnographic research methodology in palliative care needs to be considered seriously before undertaking such a commitment. Reflecting on my own experience in conducting an ethnographic study of this nature, I became aware of the personal impact on the researcher of carrying out this type of research.

The deep level of involvement required in ethnographic research of this nature led me to question the ethics of withdrawing from the participants prior to death. I had originally decided that I would disengage from participants once I had reached a level of data saturation. However, I had not foreseen the intimate ways in which I would become involved in the participants' journeys. I had not considered that it might feel ethically and morally wrong for me to engage so fully with the participants at such a vulnerable time in their lives and then leave them to complete the journey without my support. Prior to beginning the research, I was also not aware, understandably, of the many gaps in services which I would eventually identify and personally fill. Making the decision to stay the distance felt like the right thing to do, but that decision came at a cost. That cost was time, my time, and the extension of time then required to complete the thesis.

Another impact that evolves from the deep level of involvement in ethnographic research is the experience of loss and grief that occurs as each participant reaches the end of life. This

experience of loss and grief also includes a certain level of vicarious traumatisation as the researcher bears witness to the sometimes distressing physical signs and symptoms of end-stage cancer. I found that I needed to have access to prearranged support people whom I could use for debriefing after difficult fieldwork experiences. My supervisors, and a friend who worked as a counsellor, provided that ongoing debriefing and support. This support was invaluable in assisting me to process and let go of traumatic experiences, thereby lessening their impact.

Prior to conducting this research, I had experienced many personal losses and I became increasingly aware of my own grief processes being triggered by the losses I was witnessing. Via discussions with my support team and the process of reflection that I engaged in each day when writing my field-notes, I was able to maintain clear boundaries and awareness of the feelings I was reacting to. This enabled me to continue to respond appropriately.

The level of involvement required when undertaking ethnographic research in palliative care may be quite different from the ethnographic research process in other fields. When there is not a natural attrition of the population group that is involved in the research, as there was with my participants, a predetermined disengagement process would be beneficial.

9.6 Recommendations for Future Research

When I began recruiting participants I did not specify an illness type for inclusion in the research. The bulk of patients referred to hospice are people with metastatic cancer. Consequently, as a reflection of this population demographic, the participants recruited in conjunction with hospice were people with cancer. Awareness of this fact alerts me to questions regarding the process of referral to palliative care services for people with non-malignant, life-threatening illness. This is an area that requires further consideration. The question I am particularly interested in is what role palliative care services play in providing for those other population groups and whether that involvement improves the quality of life and the process of death for the individuals and families concerned.

Through the process of conducting this research, questions arose around the place of end-of-life care that warrant further investigation. For example, I would like to see research which examines family members' reflections on caring for a family member who is dying at home rather than in a care facility. More specifically, this would be a multi-centre research project that examines palliative care provision in the main cities in New Zealand and also targets rural areas. I believe that research such as this would benefit the development of future palliative care facilities and services in New Zealand. It would also highlight implications for funders of palliative care services and directly influence the rhetoric surrounding end-of-life care. In particular, the rhetoric surrounding the topics of dying with dignity, dying at home as the preferred culturally-appropriate choice, the use of acute hospital beds for dying patients, and the appropriateness of using aged-care facilities for end-of-life care.

Further research into the process of diagnosis and the role of the GP as primary carer in that process is also warranted as this remains a contested issue and has major implications for the early and potentially successful treatment of cancer. It is also an issue that has major implications for the bereavement process of family members.

9.7 Conclusion

Participants in the research took different paths to reach the same destination, the end of life. On their journeys, they were supported by palliative care services, including the hospital oncology department and the community palliative care team. The course they took was charted in Diagram 5, and the alternate paths were presented and discussed. Why each participant took his or her particular path was considered in conjunction with information about their previous experiences and prognosis.

Issues that arose in each of the findings chapters (Chapters Five to Eight) were discussed in light of the *New Zealand Palliative Care Strategy* (MOH, 2001) vision statement and aims. Issues such as the timing of referral to palliative care services were discussed by reflecting on the early recruitment phase of this research and the pattern of late referrals that was found. The need for consistent information about home support aids, and timely coordinated support being provided in the community was discussed in relation to the participants' experiences. Promoting the idea of dying at home can only be achieved when the level of support is adequate and consistent. The cultural identities of families involved in the research led to an exploration of the environments where the dying are located and found these ill-equipped. It was also discovered that the ill participants experienced a

transformation of identity after diagnosis and a process of enculturation into the health system.

At the end of life, when family members gather, the system needs to be more flexible to meet the cultural needs of the family/whanau. However, the person who is dying is not always aware that their cultural needs are being met at this point of the journey, as they are often unconscious. The uncertainty surrounding prognosis appeared to be at the crux of many issues raised in the thesis. More reliable prognoses have been achieved with the use of research instruments that provide a fairly certain prognostic score. It would seem that when an accurate prognosis is provided, there is less chance of unnecessary interventions occurring, and a more balanced focus on palliation. Even if it is not possible to provide a clearer prognosis with respect to the amount of time a person with terminal illness has left, a social worker in the care-coordinator role may help ensure that the environment and the people are equipped for this change. Care-coordinators could educate family members about the physical changes that occur so they can notice these themselves and request appropriate assistance. The findings in this thesis support the argument that when an optimistic prognosis is given, the dying individual and his or her family are often unprepared for death, and when a less optimistic prognosis is given, the dying person and their family appear to end intervention earlier and work towards acceptance of approaching death. Finally, access to information is vital for individuals and their families at the end of life. The social work focus on improving the relationship between people and their environment would suggest that social workers are ideally suited for the role of care-coordinators in this journey to the end of life.

9.8 Positioning Statement

I have often wondered how I would end this research journey that I began in 2003. What I have come to realise is that the journey never ends because there is always more to add to the story. Since completing the fieldwork component of the study, I have remained in contact with some of the participants' family members. One family member, from whom I had not heard for over a year, made contact with me when she was also diagnosed with cancer, and I was able to offer her some support. Several members of other families have stayed in regular contact with me. Three of them were the husbands or partners of those who died.

Bill was one of these three and he was diagnosed with cancer approximately one year after Joan's death (in 2007). We became good friends, and I supported him through his own journey with cancer until the end of his life in 2009. Another husband, Chris who was married to Helen, and I have become good friends, and we meet regularly for coffee. His life has moved on, as it inevitably does, but we both love to sit and talk about Helen who fought her cancer for over four years. Chris offered his support after my own diagnosis with breast cancer, in 2008, and throughout my treatment. Alice's husband Dennis has moved to another part of New Zealand, but I still receive regular text messages from him letting me know how he is.

I have also maintained contact with many of Billy's friends and family, including his sister. I received my diagnosis in the weeks prior to Billy's death, so his family and friends inevitably became aware that I was also dealing with similar issues to those they had dealt

with. His friends provided practical and spiritual support throughout my treatment, and still do to the present day. Billy's sister and I have become good friends. Throughout Billy's illness, his sister taught me much about faith and selfless service to those we love. Billy's parents also contacted me when they heard I had been diagnosed with cancer, and they offered me support as well.

From the beginning to the completion of this thesis, I have been blessed by the companionship of these many people; they have taught me so much. Although my journey with the eight life-threatened individuals came to a natural end after their deaths, my journey with their friends and family members continues to unfold.

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On University of Canterbury letterhead

Letter of Introduction

Considering Culture: Individuals' and their Families' Experiences of Palliative Care Services in Aotearoa New Zealand.

I invite you to take part in a study about individuals' and families' experiences of palliative care. My name is Catherine Hughes and I am undertaking doctoral studies in the Department of Social Work at the University of Canterbury. The desire to understand individuals' and their families' experiences with palliative care and health systems is derived from my personal and professional experiences with terminally ill friends, family members, and clients.

Enclosed with this letter is an information sheet about the study and a consent form. I would be grateful if you would read these and take some time to think about whether or not you would like to be involved in this research. It is entirely your choice and there is absolutely no pressure to become involved.

A member of the Nurse Maude palliative care team will have given you this information and they will be in touch with you to find out if you are willing to be involved. If you have any questions about the research that you would like to ask me, or if you are interested in taking part, you can tell the visiting palliative care team member, and I will make contact with you. If you decide that you want to be involved in the research, we will sign the consent form at the time of my first visit.

Thank you for taking the time to consider my invitation.

Yours sincerely,

Catherine Hughes
Principal Researcher
Private Bag 4800
Department of Social Work
University of Canterbury

Information Sheet

Considering Culture: Individuals' and their Families' Experiences of Palliative Care Services in Aotearoa New Zealand.

You are invited to take part in a research project exploring how individuals and families experience being referred to and cared for by palliative care services. This research has been discussed with members of Nurse Maude Palliative Care Services and will be conducted with the support of this service. I am interested in talking with you as your experiences may greatly help others going through the same process. When I use the word family in this research I am using this term in a very general sense. A family may consist of the traditional nuclear family unit and relatives, or it may consist of a group of friends or people that you think of as family.

Who is doing the research and why?

My name is Catherine Hughes and I am undertaking doctoral studies in the Department of Social Work at the University of Canterbury. The desire to understand individuals' and their families' experiences with palliative care and health systems is derived from my personal and professional experiences with terminally ill friends, family members, and clients. Knowledge about the people receiving health services is also required so that services can be designed to meet their needs. This research will provide vital information on the experiences of culturally diverse individuals and families receiving care.

What do I want to know?

The research will explore how individuals and families understand their involvement with palliative care services. In coming to terms with their experiences families may draw on shared understandings in order to make meaning from the process they are engaged in. These shared understandings or meanings can be said to form part of the families' cultural identity. What is of particular interest in this study, is whether, and how, people draw on aspects of their cultural identity during their engagement with palliative care services.

Cultural identity is not tied solely to a family's ethnic identity, although this forms part of their cultural identity. It includes shared beliefs and values, belonging to a particular religion, or affiliation with a specific social group. Cultural identity is also developed according to the composition of the family group. For example, the cultural identities of a nuclear family unit, an extended family network, and a non-traditional family unit, such as gay and lesbian families or reconstituted families, may be quite different or they may have certain similarities.

What is requested of participants?

Taking part in this study involves an agreement between the person referred to palliative care services and other family/whanau members, to be involved. This is because I will need to spend some time with as many members of the family as possible during the course of the research. The researcher's involvement with individuals and families will end at such

times as: the completion of the researcher's time in the field; at the request of research participants; if participants stop having contact with Nurse Maude services; or if the person referred to palliative care services dies during the research period.

The majority of the information that I need for this research will be gained just by spending time with you and your family and observing or being part of day-to-day activities. I am really flexible about the amount of time and the kinds of activities that occur in the time that I spend with you and your family, and will always work towards ensuring that your needs come first. I would like to be able to observe some of your interactions with health or palliative care services, but none of the services will receive any identifiable information about you or your family members from this study.

I may need to gain some additional information by briefly sitting and talking to you (like an interview), but will only do so if you agree to it. This interview could be taped if you agree to it, or I can just take notes while we are talking. A copy of the audiotape can be sent to you if you so wish (indicate on the consent form when I come and see you to fill it in) otherwise it will be destroyed once the term of the research project is completed. All information will be recorded anonymously, and stored in a locked cabinet, in a locked office.

Also if we are discussing something, such as an event, an item, a photo, or your feelings about something, I may ask you questions about it. The information that you share could be used as information for the research.

It is important that you know that you don't have to answer any question that you don't want to answer, or have any conversation that you don't want to have, it is totally your choice.

Your rights as a participant

You have the right to

- complete confidentiality (no names or identifiable information will be used in the writing up of the study).
- withdraw from the study at any time
- refuse to answer any questions and/or request that the tape be turned off during the interview
- ask any further questions about the study at any time
- have your audio-tape returned to you at the end of the research
- receive a copy of the findings and/or your transcript at the completion of the research
- request the researcher to leave, without having to withdraw from the study.
- free support or counselling during the course of the research (This resource is available to all members of the family when a person is referred to the Nurse Maude Palliative Care Service. Alternative contacts can be provided by the researcher)

If you want to meet with me to discuss the study in more detail before making a decision about being involved, I would be very happy to meet with you at a time that suits you. Just let a member of the Nurse Maude palliative care team know and I will contact you. If members of your family/whanau would like to know more about this research, or if you would like to have them present for support, I can meet them at the same time. I am happy to meet with you at home or anywhere that you feel is suitable. It is important that you know that your participation is voluntary and if you decide not to take part, this will not affect any future care or treatment that may be required by you or by any other family member.

The research has been reviewed and approved by the Canterbury Ethics Committee, The University of Canterbury Human Ethics Committee, and Nurse Maude Association Ethics Committee.

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Consent Form

Considering Culture: Individuals' and their Families' Experiences of Palliative Care Services in Aotearoa New Zealand.

I have read and understand the information sheet for volunteers taking part in the study designed to gather information from individuals and families about their experiences with palliative care services. I understand that taking part in this research is voluntary (my choice) and that I may choose not to answer any questions that are asked of me. I also understand that my participation in this study is confidential and that no material that could identify me will be used in the writing up of this research. I know who to contact if I have any concerns or questions about this research. I have had time to consider whether to take part in this research. I also understand that I can withdraw from this research at any time with no consequences for myself or any other family members involved.

Having understood the above statements I (name) _____ give my consent to be involved in the above research and to have further contact with the researcher.

Please circle one. YES/NO

I give my consent to be interviewed for this research, in negotiation with the researcher.

Please circle one. YES/NO

I give my consent for the use of an audio-tape at times that it is deemed appropriate by the researcher and myself.

Please circle one. YES/NO

I would like the audiotape returned to me at the completion of the research.

Please circle one. YES/NO

I would like to receive a typed transcript of my interview.

Please circle one. YES/NO

I have read the information sheet and the above statements and hereby agree to give my informed consent to be involved in this research project in the manner indicated above

Participants Signature _____ Date ___/___/___

Catherine Hughes
Principal Researcher

Private Bag 4800
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University of Canterbury

Interview Guide

Considering Culture: Individuals' and their Families' Experiences of Palliative Care Services in Aotearoa New Zealand.

This study will utilise an open-ended interviewing technique where the precise wording of the questions has not been predetermined. Interviews may be conducted over a period of time, depending on availability of participants. The main topics to be covered in the interviews are listed below.

Topic Area 1: Culture

- Participant's general understanding of the word *culture*
- Participant's understanding of own cultural identity
- How much importance do participants place on cultural identity?
- Has there been any change in the importance placed on culture since terminal diagnosis (either as patient or family member)?

Topic Area 2: Awareness of terminal diagnosis

- Type of illness (patient or family member)
- Information given to participant about illness and prognosis (either as patient or family member)
- Discussions participant has had with others about diagnosis.

Topic Area 3: Health system

- Participant's involvement with the health system focusing particularly, but not exclusively, on palliative care (either as patient or family member)
- Participant's feelings about their involvement with above systems
- Where would participant want to be when death (of self or other family member) is imminent?
- Factors that enhanced participant's experiences with health system
- What negative aspects would participant identify and what factors could have reduced these?

Topic Area 4: Issues of concern or importance to participant

- What issues have arisen as important during their process as ill person or as family member of ill person?
- Is there anything they would have liked to have done differently during own illness, or of illness of other family member?

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4th July 2006
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Dear Sarah

I hope you are well and that you have been able to spend some nice time with Sophie, Paul and the kids since they moved to Australia.

I have included some copies of transcripts when you were present with Jack. These transcripts are confidential to each of you that were present at the time the information was being collected. These transcripts will not be sent to any other family members, but they will receive their own transcripts. Any discussion that occurred and is recorded here is kept in the utmost confidentiality and you will be the only person apart from me that sees these transcripts. It is therefore, your choice if you choose to share parts of it with other family members.

I have also included a letter which contains reflections of my time with Jack and all of you. I want to thank you for allowing me to spend time with you, your family, and especially Jack. My time with him and all of you was very precious and I was deeply saddened when Jack passed away. I will however, remain eternally grateful for the time and energy that Jack, and all of you, devoted to my PhD research.

Warmest regards

Catherine Hughes

Appendix F

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To the family of Jack

I am writing this letter to all of you to thank you for allowing me to be part of your lives at a difficult and important time. Allowing me to walk the journey through palliative care with Jack and each of you has provided invaluable information for my PhD. I want to give you an overview of my thoughts and feelings about my time with Jack and with each of you. Each of you will have different pages of transcripts attached to this letter.

When I first met Jack he was receiving chemotherapy treatment but this was making him very sick, and he soon made a decision to stop the treatment. I began spending time with him at home, developing an understanding of his thoughts, feelings, and process of living with cancer. I was able to learn about the type and frequency of contact that Jack had with oncology services and the community palliative care team, and how this contact affected him. Jack told me that he had gone through a protracted process of dealing with health professionals prior to his diagnosis of cancer. From what I understand this process is frustratingly common. Jack expressed his anger about the multiple misdiagnoses he was given and his concern that if he had been diagnosed earlier he may have had a better chance of surviving. In spite of the misgivings Jack had about some doctors he had seen, he had great respect for all the oncology health professionals who were involved in his care and he always thanked them for their support.

I began to pick Jack up, or meet him and Betty at the hospital for appointments. Through this process I learnt that time was very important to Jack, and we arrived early for whatever appointment we were attending. I also learnt to do a slow jog in order to keep up with him through all the hospital corridors. It really makes me smile when I think of him and the way he used to go full speed at everything. Through spending time with Jack and each of you, I was able to learn about various types of palliative treatment that are offered, and how treatment provides a sense of hope that is very important. Hope was vital to Jack and he held on to much hope that one of the approaches that he tried would slow down his cancer so he could have more time with all of you. If one of the doctors or nurses made a suggestion about what might help, Jack was willing to give it a go. He volunteered for research being done at the hospital that involved drug trials, and of course stayed involved in my research and data collection. Jack was also very active in decision making about his illness and treatment and made a point of asking for any information that was available.

Through spending time with Jack I learnt how important friends and family were to him and the central role you all played in his life. Jack explained that his biggest concern was the impact that his illness and dying would have on his family. Jack was very proud of all of you and spoke often about the importance of family and the regrets that he had as a father and husband. Jack and I explored his beliefs about family values and parenting and discussed how these have changed over the generations. Jack said that he came from the old school that believed that children should honour, obey and respect their parents. He said that although he believed that these values were important, he now believed that it was more important to let your children know that you love them. He explained that he hadn't told all of you often enough that he loved you, and now he realised how important that was and he was going to make a point of doing so before he passed away. Although Jack told me that he didn't feel he had let all of you know how much he loved you, I could see how excited he would get when he knew any of you were coming to visit. I know he was looking forward to his son's wedding and often spoke of this. He loved the time he had with all of you and I know he treasured every moment. Jack had an incredible inner strength that he drew on constantly to keep himself going and when he knew that one of you were coming to visit, he would do all he could to look good. Jack also spoke very fondly of his extended family members, and many other people in his life. I had the honour of meeting many of Jack's special people in the last 3-4 weeks of Jack's life, while he was in hospital, and to witness the pleasure it bought him to see everyone.

I found Jack to be very open and trusting of my presence in his life and he soon made it his task to ensure that I got all the information that I wanted or needed. Even in the week before Jack passed away he sat up in bed and said to me: "Okay interview me now because this may be your last chance". I was very concerned about him using up what little energy he had, but realised that it was important to him that he contribute information for this research. In effect it became one of his final projects. He also became very caring about my well being and started to develop a plan for my future: we had quite a few laughs about that. Jack did have other projects on the go too and seemed to be on a mission to get his affairs in order before he passed away. I know from what all of you have told me that Jack always had list of jobs that he wanted to complete, and that it was important to him to keep active. I also saw how frustrated Jack became when he was unable to get things done because of the pain and the limitations of his illness. However, he didn't let this get him down too often, and was usually bright and cheerful when I arrived for a visit.

I know that any letter about Jack needs to include mention of the holiday home. Jack decided that I should go and visit the holiday home because he felt that it would tell me a lot about him. So on a lovely sunny day I headed off and spent a couple of hours wandering around the holiday home and learning more about Jack. My next visit to the holiday home was to meet Sophie and Sarah. I arrived just as Jack's boat was heading back to the boatshed. Jack's constant companion, his dog, was hanging over the edge of the boat like an old deck hand. It was lovely to see Jack so happy spending time with his two daughters. Jack introduced me to them and it soon became evident that this whole boat and fishing thing was much more Sarah's forte, than Sophie's, so Sophie and I headed off for a wander through the bush. The holiday home was very important to Jack and I know that he had hopes of retiring there and living out his golden days in peace and quiet. He was very proud

of all the work he had done on the home and gave me the grand tour of the renovations and explained where he was going to build the new bathroom. I know Jack didn't get to live out his dream of retiring to the holiday home, but he did get to spend one last time with all of you there and he enjoyed it immensely. In the weeks following, as Jack got sicker, he often spoke about that weekend and said how happy he had been.

I consider myself fortunate that Jack was willing to volunteer his time and energy to help me with my PhD research, and that each and every one of you was also willing to allow me to spend time with your family during a period when time with Jack was so precious. I will always be grateful to all of you for opening your hearts and minds to me, and I wish you all well in the future.

Warmest Regards

Catherine Hughes

8.7.05 Participant One
Jack – Ward 27, 10.30am
Sarah's Phone call

I arrived at 10.30 am and walked into Jack's room. Jack is looking better today, he says that he improved yesterday afternoon. They feel they got on top of the pain after lunch. Mary (nurse) came and sat down with us. She said "he's got a new lease on life today". I said that I had noticed that. Mary is lovely with Jack and very caring. Mary is Jack's nurse today. She said to me, "I can't believe the change in him from yesterday". I said that I was amazed. She said "I've never seen anyone take that much morphine and live". I asked Mary to explain to me how they are giving Jack his drugs. She explained that he is on subcut morphine and morphine elixir and tabs. She said that he is also on Ativan, which helps him to just chill out. He is also on a drug called Tartrate, but that he is on large morphine dose. The phone in the room rang and the receptionist came in and picked it up and said it was for Jack. He said hello and then said hello dear, yes I'm feeling much better today. His daughter Sarah was on the phone and I can tell that she is telling him that I had sent her an e-mail yesterday to let her know that Jack was not doing so well. He said that he did have a bad day but he was doing better now.

This is what Jack was saying on the phone. He said "I've got to make the most of my children, I love all of you. As soon as your brother comes over at the weekend, 5,000.00 will go his way and the same your way and Sophie's. No, no, just shut up, I've told mum, also putting 1,000.00 in trust. It's a wedding present for your brother, if you want to buy some furniture then go for it, does that sound better, okay, 5000.00 comes off the mortgage. I'm not 100%. Don't worry about me. I'll bounce back. We will have to fix you up for these phone calls. Look I really love you, I know it's hard, so hard, not knowing what's going to happen to me.

Mary the nurse was still sitting with me and we were talking quietly. She explained that Jack improved after lunch yesterday and got up and had a shower and brightened up a lot. I asked her about his colour. She said yes he is a bit flushed isn't he. She said he's not sweating though. I said that he definitely seems better. She said he seems like he has a new lease of life today.

Jack asks Sarah (his daughter) if she would like to speak to the nurse. Sarah obviously says yes and Jack hands Mary the phone. Mary reassures Sarah that Jack is vastly improved today, and then hands the phone back to Jack. Then I hear Jack ask his daughter if she would like to speak to me. Jack hands me the phone and Sarah says hello. I tell her that Jack is vastly improved from yesterday and that he hardly looks like the same man. I tell her what the nurse had said about never seeing anyone take that much morphine and live, as Jack did yesterday. We chat for a while and she thanks me so much for the e-mails. We say good bye and I hand the phone back to Jack for his final goodbye. He tells Sarah that he loves her again.

Mary leaves the room just as friends of Jack's arrive. I stand up and move away from the bed so they can sit next to Jack. The friends ask Jack if he knew that they had visited him yesterday. Jack said "no". They explain that Jack was sleeping and that they sat with him for ½ an hour. Jack says I knew you'd be in; you're some of my best mates. They reply

that they have been really busy but Jack is important to them. They talk about their son for a while and then they say, “It’s warm in here, isn’t it, it’s cold outside, you’re in the best place Jack”.

Jack says that he needs his medication and his friends hand him the bottle. He takes some Clorazapan, Rivont – 2-3 drops. I ask Jack what it does and he replies that it is a relaxant. He says that he will take it now because he is going to go for a walk in a minute. Jack says I have to take my shopping bag with me. He is referring to his catheter bag.

Jack then looks at me and says that the hospital social worker came up and asked Jack about me and what he thought of me. Jack said that I told him that he couldn’t wish for a better co-worker if that was what he was thinking about. I tell Jack that that was lovely. He said well I think you would be a real asset to their team.

Just then the social worker walks into the room, and asks Jack how he is. Jack says “good and not so good”. Jack explains that he is still in quite a bit of pain, but he is better than he was yesterday. The social worker says well let me know if there is anything I can do for you. I see you are in good hands right now so I will leave you to it. Just after the social worker leaves, another visitor arrives and I can overhear Jack keeping his other visitors amused. He is telling them that he wants to get the catheter bag removed, Jack says that they will hear me screech if it comes out. Next Harry and Betty arrive so I say that I will pop back and see Jack later on or tomorrow.

Left 1.45pm