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**Talking about end-of-life care for older people
in a rural New Zealand community**

A thesis presented in partial fulfilment of the requirements for the degree of

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New Zealand.

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“For all of us who cannot know anything for sure, death is the ground on which the whole world can speculate in common. It is also the ground on which we can stand together, to support each other, and to show each other, especially to the dying and the bereaved, that our minds and spirits are with them, that neither they nor (we hope) we die alone.”

Young & Cullen (1996)

Abstract

Rural experiences are under-represented in the end-of-life care literature. In addition, population projections indicate that the numbers of older rural people are increasing. In an attempt to better understand their needs, this study considers how older people experience end-of-life (EOL) care in a rural New Zealand setting. Having responded to local media and community notices, seven participants, who in the last eighteen months had cared for someone over the age of 65 with a terminal illness, spoke about their experience of rural EOL care. Their stories were then transcribed and analysed, using narrative analysis. Participants spoke about similar issues, but from different, sometimes conflicting, perspectives. Positioning themselves primarily as carers, rather than as rural people, the participants' stories nevertheless reflected their social location for caring, as they talked about exhaustion and needing 24 hour support; limited access to specialist palliative care services; and the difficulties of caring for people with complex needs. At the same time they spoke of the joys and rewards of caring. The ambivalence and conflict evident in the stories indicates the participants' location in a particular place and time in the history of dying. Caught between two paradigms of care, these participants vacillate between the desire for the empathic, compassionate care of yesteryear and the best that modern medical technology can offer. Discussing when to continue and when to stop medical intervention produced the most conflicting perspectives. However, all agreed that having time to form therapeutic relationships is a key component of EOL care. Overall, the stories demonstrate that the multiple and complex experiences of older rural people render stereotypical assumptions about rural life and dying at home problematic. However, as this study demonstrates, simply talking with people provides access to and understanding of their lived realities. Incorporating this kind of approach in future rural EOL care planning will move us closer to achieving contemporary goals of positive ageing and dying well.

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Table of Contents

Abstract.....	v
Acknowledgements.....	ix
Table of Contents.....	xiii
List of Figures.....	xix
List of Appendices.....	xxiii
Chapter One: Introduction.....	1
Chapter Two: The Changing Face of Death and Dying.....	7
Living in fear and denial.....	9
Familiarity and ritual.....	11
Enter the individual.....	13
Beautiful death of the romantic era.....	14
Invisible death and the mystery returns.....	14
Denial denied?.....	16
The modern face of death in New Zealand.....	16
The awareness conspiracy.....	19
Attitudes and beliefs in New Zealand.....	20
Summary.....	21
Chapter Three: Towards a ‘New’ Way of Caring.....	23
Reviving death.....	25
Terminal illness: A new phenomenon.....	27
Population Ageing.....	27
Dying as a process.....	28
Hospitalisation of death.....	29
Hospice.....	29
Hospice in New Zealand.....	31
Challenges to hospice care.....	31
Palliative care.....	32
Generalist and specialist palliative care.....	33
End-of-life Care.....	35

Dying well: good, well-managed, appropriate or just good enough?.....	36
Dying well.....	36
The good death.....	36
Alternative ways of talking about dying well.....	39
Place of death.....	39
Dying in rural New Zealand.....	41
Social policy.....	42
Living and dying in a rural setting.....	43
Services and resources: access and limitations.....	44
Caregiving burden.....	45
Information, education and training.....	45
Summary.....	47
Chapter Four: Methodology.....	49
Social constructionism.....	53
Narrative psychology.....	54
Narrative analysis.....	55
What is a narrative?.....	55
Different kinds of narrative analysis.....	56
An overview of the analysis process.....	57
The researcher as <i>bricoleur</i>	59
Chapter Five: Method.....	61
Participants.....	63
Procedure.....	65
Ethics.....	65
Recruitment.....	65
Interviews.....	68
Analysis.....	69
Chapter Six: Results and Discussion.....	73
Telling a story.....	77
Rural stories.....	82

Travelling.....	82
Good old-fashioned neighbourliness.....	84
Mobility and diversity.....	91
Getting services right and accepting help.....	96
The burden of caring.....	100
To treat or not to treat: Part one.....	109
Caring stories.....	112
Changing needs in rest homes.....	112
To treat or not to treat: Part two.....	115
Treatment: 9 to 5, weekdays.....	119
Caring is “just being there”.....	124
The joy of caring.....	126
Different standards.....	129
To treat or not to treat: Part three.....	134
To treat or not to treat: Part four.....	141
Dying is natural.....	146
A time of transition.....	149
Summary.....	158
Caring.....	158
Social location of caring.....	161
Limitations.....	164
Future research.....	165
Implications of this research.....	165
Chapter Seven: Conclusion.....	167
References.....	171
Appendices.....	191

List of Figures

Figure 1: Constructing a meta-narrative as part of my thesis..... 72

List of Appendices

Appendix A	Community Notice.....	193
Appendix B	Revised community Notice.....	194
Appendix C	Newspaper Article.....	195
Appendix D	Information Sheet.....	197
Appendix E	Consent Form.....	201
Appendix F	Demographic Form.....	202
Appendix G	Demographic Information.....	203
Appendix H	Transcription Notation.....	204
Appendix I	Symbolic Quilt.....	205

Chapter One:

Introduction

“Live how we can, yet die we must”.

William Shakespeare, King Henry VI. Part III, Act V.

Death is a universal human experience. In fact, death is the only future life event that we can anticipate with any certainty. Yet how we experience our own dying is far from universal. Just as we live in different ways, every person experiences their own dying in a unique way (Feifel, 1990; McKechnie, 2007), with individual differences such as personality, age, gender and type of illness all contributing to “a death of one’s own” (McNaught, 2002). However, although how we die may be unique to every individual, it does not involve just the dying person. Rather, the dying process is “typically an experience lived out in social contexts” (Corr, Doka & Kastenbaum, 1999, p.241). Family, friends, informal and formal carers and health specialists interact with the person who is dying as well as with each other, sharing, or withholding, information and support. It is through relationship networks such as these, that a particular experience of death is constructed (Hedtke & Winslade 2004). From a wider perspective, each experience is located within historical, cultural, and political contexts, all of which influence general attitudes and create identifiable patterns in how we perceive and respond to dying and death (Walter, 1994). This in turn, influences the kind of end-of-life (EOL) care that dying people expect and receive.

Needs at the end of life encompass not only physical, but also psychological, spiritual, social, and even legal issues, making death “...manifestly too complex to be in the special sphere of any one discipline” (Feifel, 1990, p. 537). Thanatology, the study of death and dying, is therefore a multi-disciplinary exercise, considering for example, medical, psychological, sociological, and anthropological points of view. Each of these disciplines employs its own specific theories, methods and practices, which influence their way of investigating and

understanding the topic. However, it is possible and indeed necessary to be aware of what each field has to say. This enriches our understanding of complex issues and is indicative of the kind of multi-disciplinary collaboration that can maximise the quality of EOL care (Gelfand, Raspa, Briller & Schim, 2005). To this end, although the work presented here primarily considers the psychological aspects of death and dying, it also incorporates findings from other disciplines.

It is not easy for most of us to talk about death. In the back of our minds, we know that it is inevitable, yet we spend our lives trying to prevent, or at least delay the moment of death for as long as possible. Characteristic of the post-modern world in which we live is a plethora of professional advice and recommendations for reducing risk or improving health in the hope of extending one's lifespan beyond the conventional three score years and ten. Indeed, as significant technological advances in medical science over the last century have dramatically reduced rates of infectious disease and improved surgical outcomes, life expectancy has increased, particularly in the Western world (Lyons & Chamberlain, 2006). Furthermore, having come to expect that modern medicine can prolong life, or find a miracle cure, sick people are less likely to accept an unfavourable prognosis and just go home to die (Bourdieu, 1977). Increasingly, we have come to rely on health professionals to manage our illnesses and our dying.

However, what happens when the doctors can no longer manage a disease or offer hope for a cure? How prepared are people to face something that may have been actively resisted or at least implicitly denied over an entire lifetime? How should care proceed, in order to preserve the best quality of life possible until the moment

of passing? How much choice do individuals actually have? Who has the control, if any, in the final weeks, days and hours? Can we ever be fully prepared for the hour of our death?

This research project considers questions such as these, by listening to stories that people tell about care at the end-of-life, the kind of care given to and received by people whose curative or disease-modifying treatment has to all intents and purposes ended. The stories are about older people residing in rural New Zealand: a particular group of people with their own unique challenges and strengths. The relative numbers of older people living in rural areas seems likely to increase in the future (Dunstan & Thomson, 2006), yet we know relatively little about the experience of EOL care for people in this demographic group. This study brings their experiences into focus, thereby adding a contextualised perspective to the existing literature on dying well. These stories represent a further layer of knowledge that has the potential to inform future EOL care for older, rural patients.

The next two chapters set the scene for the research that follows. Chapter Two considers attitudes towards death and dying in Western civilisation, from pre-historic times through to the present day. This locates the contemporary experience of death and dying within its socio-historical context, providing a backdrop against which to understand the participants' stories as they unfold. Chapter Three looks at contemporary EOL care, again from a Western perspective. Beginning with the revival of interest in death and dying, the discussion follows the beginning of hospice care through to the introduction and

explanations of palliative care, focussing in particular on care for older people. Moving closer to home, the chapter concludes with a discussion of rural EOL care, beginning with a review of the social policy that underpins ageing, and indirectly EOL care, for older people in New Zealand in general. When appropriate, articles written about care from a New Zealand perspective are incorporated, however the rural literature review draws entirely on international experience. This leads into the rationale for this particular study, the methodology that informs it, and the methods used, in Chapters Four and Five. The study results are presented, analysed and discussed in Chapter Six. The thesis concludes with Chapter Seven.

Chapter Two:

The Changing Face of Death and Dying

*“Though all becomes dead eventually, the paths to this
eventuality have not all been the same; we have not always died
in the same way”.*
(Kellehear, 2007).

Understanding how people died in earlier times provides a useful insight into the social forces that shape contemporary relationships with dying and death and influence personal attitudes (DeSpelder & Strickland, 2005). This chapter therefore considers how our attitudes and experiences have changed throughout civilisation. Because this study explores rural EOL care in a developed country, the following review draws mainly on the literature presenting a Western perspective. However, using the term ‘Western’ is problematic. Firstly, it is acknowledged that different cultures understand and experience dying and death in differing ways (Seale, 2000). Secondly, the assumption that all Western experiences are homogenous is in itself problematic, when the experiences within one culture may be as diverse as between cultures. Indeed, one of the reasons for this study is to understand the experience of a particular ‘microcosm’: older rural people, embedded within New Zealand society. Finally, although the literature specific to New Zealand is growing, the experiences of other major Western countries inform much of what we know about dying and death, thus providing the basis of this review. Therefore, bearing in mind these difficulties, the term ‘Western’ is best understood as more of an “intellectual construction than an empirical reality” (Lawton, 2000, p.3).

Living in fear and denial

More than half a century has passed since Gorer (1955, as cited in Ariès, 1976) suggested that death in the twentieth century had replaced sex as the taboo topic of contemporary societies. A cultural anthropologist with an interest in psychoanalysis, Gorer stated that whereas in the Victorian era death had been a matter for discussion and sex was something that occurred behind closed doors, by

the middle of the twentieth century, sex could be openly discussed but the equally natural process of death had become shameful and hidden, especially from children. Taking this further, Becker (1973) argued that our whole lives are, in fact, organised around the fear and denial of death. While later studies suggest that this fear may be a learned, as opposed to innate, response (Kastenbaum, 2000), Becker believed that the fear, or terror, of death is natural and is present in everyone. This was the first major challenge to Freud's earlier theory that death anxiety is a neurotic cover-up by people trying to deal with unacknowledged or unresolved childhood conflicts (Kastenbaum, 2007). Highlighting the paradoxical nature of the human situation, Becker argued that a fear of death is a survival strategy, motivating behaviours essential for self-preservation, thus ensuring the survival of our species, yet at the same time constantly living with the fear of dying is deeply counterproductive.

This is one explanation as to why, most of the time, most individuals only vaguely acknowledge death (DeSpelder & Strickland, 2005). Unless forced to confront it, people tend to relegate thoughts about their own dying to the back of their minds, looking instead towards their future with optimism, often following expert advice in order to live a full and healthy life (Crossley, 2000a). However, when death does catch up with them, most people do not know how to cope without the help of health professionals (Byock, 1997). Indeed, doctors and institutions have gradually taken over the care of dying people, particularly since the middle of the twentieth century, which has led to dying becoming primarily a private and technological affair (Wood & Williamson, 2003). Similarly, it is now commonplace for funeral directors to take over the care of a body immediately

following death, removing it out of sight until it is prepared for viewing, followed by a moving, personalised ceremony typically ‘softened’ with music and flowers (Becker, 1973). Becker suggests that practices such as these not only minimise the harsh reality of death, but also demonstrate the role that society has played in strengthening individual defences against death anxiety. However, according to French historian Philippe Ariès (1976, 1981), it is precisely because of the removal of death from everyday life that people living in modern Western societies live in denial, if not fear, of death.

Familiarity and ritual: “*Tame death*”

In any discussion of the social history of dying Ariès (1976, 1981) is arguably the most widely quoted historian of recent times (Wood & Williamson, 2003). As a result, Ariès’ work has been influential in shaping subsequent perceptions of how we might care for dying people. Focusing on how people experience and understand death, he identified four, at times overlapping, periods of change in Western attitudes, beginning with the “*tame*” death *circa* the early Middle Ages. Death for medieval people was an anticipated, natural part of life and a communal event. Individuals were not autonomous and isolated; they were involved in the dying process as integral members of the community, routinely witnessing death as they sat with the dying in their final hours. Not only did they personally experience the deaths of others, but also their own personal observations generally foretold when they themselves were gravely ill, and when death would occur, which they more or less controlled through ritual processes. Furthermore, because people understood death as the collective destiny of humankind (DeSpelder & Strickland, 2005), they met it with resignation, whether at home or resulting from

battle. They hoped for a long and peaceful sleep, after a physical passing and before a collective judgment, which offered the possibility of atonement and eternal salvation (Feifel, 1977). In this way, people not only expected there to be life after death, they also tended not to fear it.

This belief in a post-death judgement reflects not only Christian beliefs, but also Stone Age practices when death was something that happened suddenly, through accident or misadventure. Although people were aware that death would occur at some point, there was generally no time for preparation or personal control of the dying process. Instead, the dying experience occurred after death, with surviving kin or group members carrying out the social processes that ensured a smooth transition on the ‘otherworld’ journey (Kellehear, 2007). Therefore, it was important for the dying person not to have alienated those who would be responsible for their fate in the after-life.

It was during the Stone Age that humans began to realise the advantage in preparing and planning for their otherworld journey themselves, rather than relying on the beneficence of kith and kin after the event. Food and weapons for the ‘journey’ could be organised in advance as well as plans for family or tribal succession signalling the beginning of what Kellehear (2007) describes as a ‘dying’ in this world. Thus, Kellehear presents a counter-argument to Becker’s (1973) denial of death thesis, suggesting that it is the *anticipation* of death, and the preparation for an ‘after life’ beyond biological death, that “created the psychological, social and spiritual shape of all subsequent dying behaviour” (2007, p.46).

Enter the individual: “*One’s own death*”

According to Ariès (1976), dying individuals’ preparation and management of their own affairs before biological death intensified during a later period in human history, which he describes as a preoccupation with “*one’s own death*”. Whereas the Church had always assured its followers of collective resurrection on the Last Day, by the twelfth century people had begun to concentrate on their own deaths, worrying about and taking responsibility for their own selves, and fearing judgement for their personal actions, good or bad. By acknowledging that “I will die my own death” (DeSpelder & Strickland, 2005, p. 94), people reflected a growing awareness of the self, as individuals, rather than as members of the collective group. In addition, as religious and secular elites accumulated wealth, increased preparations and plans for the disposal of material goods became necessary prior to death.

Eventually, through the 1500’s and 1600’s, as reason and intellect usurped the authority of the Church, science gained ascendance over religion. During this time, people became increasingly ambivalent about divine judgement as statistical probability replaced sin as a means of predicting one’s fate and the medical categories of normality and health replaced concerns with morality (Walter, 1994). Thus, death became an event able to be calculated, manipulated and shaped by human beings (DeSpelder & Strickland, 2005). By the nineteenth century those doing the ‘shaping’ were not individuals but the professionals in medicine and the funeral industry (Kellehear, 2007). At the same time, at a societal level, industrialisation caused families and neighbourhoods to fragment, depriving people of the emotional and social support to cushion the impact of death (Feifel,

1990). This marked the beginning of a change in how people were cared for at the end of life that has remained an important issue for modern day planning and practice.

Beautiful death of the romantic era: “*Thy death*”

By the nineteenth century, the concerns of the Middle Ages, such as the fate of one’s soul or reputation after death, had been replaced by a fear of how the bereaved would cope after the passing of a family member. Ariès (1976) used the phrase “*thy death*” to capture the bereavement experience whereby losing a significant other had become more important than the experience of dying itself. Passionate expressions of grief, typical of the Romantic era, elaborate mourning rituals, and memorials to the dead became the norm (DeSpelder & Strickland, 2005). Victorian death was beautiful, with a post mortem reunion with a beloved being something to look forward to. This is an afterlife belief that has remained even to this day. It was also during the nineteenth century that the nuclear family emerged, replacing both traditional community values and early modern individualism and bringing with it the notion of privacy (Ariès, 1981).

Invisible death and the mystery returns: “*Wild death*”

Over a period of more than a thousand years, despite shifting emphases, for example from collective to individual, religious to secular, and pastoral to urban or industrial, dying had remained a public event. However, by the mid-twentieth century, customary signs of mourning had all but disappeared as people rebelled against the over the top funerary and mourning practices characteristic of “*thy*

death” (Feifel, 1990). In addition, technological advancement, particularly following World War II, had led to the ‘medicalisation’ of healthcare. What had once been a social, public affair, yet with some individual control, had become increasingly private and hidden from view as care of the dying shifted into hospitals and institutions and into the control of professionals (Mellor & Shilling, 1993). This process of privatisation, or medicalisation, replaced natural death (Illich, 1976), with a modern experience of dying that Ariès referred to as “*forbidden or wild*”. Ariès used these terms not so much to describe a kind of death that was violent, but rather, because of technical intervention, was no longer natural or “*tame*”. Furthermore, as death and dying became less familiar in daily life it once again became shrouded in mystery. This invisibility, Ariès argued, contributed to the denial of death: as death moved out of sight, it became easier to put it out of mind.

Although there is some dispute as to when death, and particularly the death of older people, disappeared from daily life (Minois, 1987 and Vovelle, 1983, as cited in Wood and Williamson, 2003), much of the recent academic literature supports Ariès’ argument that dying and death has become invisible in advanced Western civilisations. For example, Hockey’s discussion of the contemporary separation of living and dying suggests that by the mid- twentieth century, home, “the space in which living takes place” was no longer an appropriate place to die (1990, p.36). Similarly, Lawton (2000) describes how increasing institutionalisation and medicalisation has led to the sequestration of the dying, supporting Elias’ argument that:

“never before in the history of humanity have the dying been removed so hygienically behind the scenes of social life; never before have human corpses been expedited so odourlessly and with such technical perfection from the deathbed to the grave” (1985, p. 23).

Denial denied?

In the last forty years, there has however been a concerted effort to bring dying and death back into view. In fact, the work undertaken by social scientists in the second half of the twentieth century may have led to the preceding claims becoming somewhat outdated (McNamara, 2001). For example, there now exists a tension between denial on the one hand and increasing interest on the other, leading Walter (1994, p.2) to suggest that we have become “a society obsessed with death, not one that denies it”. According to McNamara, this may be because drawing attention to Western society’s apparent denial of death sparked a desire to understand more about the experience itself, or it may be because of changing demographics and epidemiology.

The modern face of death in New Zealand

In developed countries, the age distribution of dying people has significantly changed over the last century, with a greater proportion of deaths now occurring in older age. New Zealand is no exception. In 2006, three-quarters of the people who died were over the age of 67 compared with only 5% under 40 years of age (Statistics New Zealand, 2007). This is attributable to an ageing population, increased life expectancy and a dramatic decline in infant mortality, which is now around a quarter of the rate of 40 years ago. At the end of the nineteenth century,

although life expectancy in New Zealand was ahead of other Western countries, around 10% of Pakeha children were likely to die before they reached 45 and around half of Māori children died before the age of ten, (Pool & Cheung, 2003).

Because infant mortality rates were much higher than they are now, death was a more common experience and perceived as a natural part of life. Furthermore, before the middle of the twentieth century, New Zealanders had been through an influenza epidemic and two World wars, meaning that death was very much in people's consciousness. Since then however, life expectancy has since risen steadily. Now, a newborn boy and girl in New Zealand can expect to live to the ages of 78 and just over 80 respectively, which is comparable with other OECD countries. Life expectation for Māori however still lags behind, currently just over eight years lower compared to non-Māori (Statistics New Zealand, 2008a).

Associated with population ageing are the kinds of illnesses from which people suffer and die. More than half of the deaths of people over 65 result from the chronic illnesses of old age, such as heart disease, respiratory disease and cancer. These diseases tend to follow a slow, progressive course that may last for months, if not years (DeSpelder & Strickland, 2005). Because of this, many people may not witness the death of someone close to them until well into middle age or older, and may have only ever seen someone die on television or in the movies. Thus, familiarity with death within society as a whole has decreased, leaving people ill prepared to discuss death and dying openly. Relatively few adults, including older adults, have discussed their own preferences for care with a close relative or friend, making it difficult for others to help ensure their wishes are met

(Department of Health, 2008). In fact, for most people it is not until a family member or friend dies that they have any contact with death at a personal or meaningful level (Lawton, 2000).

In addition, the processes of individualisation and secularisation that had begun centuries earlier have left many people uncertain as to what to expect or how to behave when confronted with dying and death. This may explain the anxiety that many people experience when told that they have an incurable illness. For many people, the dying process has become more fearful than death itself, exemplified by their concerns about tangible things such as when and how they will die (Byock, 1997; Lawton, 2000). For example, in the inspirational book *Tuesdays with Morrie* (Albom, 1998), Morrie Schwartz described being more concerned about having someone attend to his personal toileting needs than he was about dying. Furthermore, many people experience awkwardness when relating to someone who is dying, especially with regard to broaching the subject of impending death (Elias, 1985). It seems that we no longer know what to say to people who are dying or bereaved, or how to say it (Walter, 1994). According to Mellor and Shilling (1993), the meaning of death is a socially and communally constructed phenomenon, and therefore, when death became hidden from view a language for dealing with death ceased to exist. In this respect, it may be a lack of experiential knowledge, rather than the denial of death *per se*, that characterises death in postmodern society.

The awareness conspiracy

An important part of the argument that death had become a taboo subject in the twentieth century was that it was dangerous for society and morally wrong not to speak about dying (Zimmerman & Rodin, 2004). Glaser and Strauss' (1966) seminal study no doubt stimulated the notion that it is wrong not to discuss dying, particularly with respect to disclosure of a terminal prognosis. Their observations of people dying in hospital, which focused on caregiving activity rather than the behaviour of dying people (Kellehear, 1990), revealed four different states of awareness of dying, ranging from open to closed awareness. At that time, closed awareness, whereby knowledge of impending death was hidden from dying people, was most common. One explanation for this is that death in the abstract is easier to discuss than one's own death or the death of a close friend, relative or patient and because death is upsetting, people tend to avoid it as a subject of conversation. While appearing to support the denial of death thesis, the practice of avoiding discussions about death may be as much about wanting to maintain smooth relations and conduct as it is about denial (Kellehear, 2007).

Since the Glaser and Strauss study however, open awareness has become the most prevalent awareness context, particularly for people with cancer (Seale, Addington-Hall & McCarthy, 1997), and indeed is an implicit component of hospice philosophy. Concomitant with this are changing expectations regarding the active participation of patients and family members in decisions relating to their own care. Yet tensions remain between the desirability of speaking about death and the natural difficulty of engaging in such conversations. Given that around 300 million people a year may need palliative and EOL care (Singer &

Bowman, 2002) the need to resolve these tensions in order to be able to discuss death in a health care setting is evident, especially if choice and control are to be exercised by those who are dying, and their caregivers.

Attitudes and beliefs in New Zealand

Given that this study takes place in a district where almost 97 per cent of the population identify as NZ European (Statistics New Zealand, 2003), this review has concentrated mainly on Western perspectives of death and dying. Therefore, the diverse attitudes and beliefs around death and dying that exist in a multicultural society such as New Zealand are noticeably absent from the preceding discussion. For example, a Māori person reading this review may not identify with the denial of death thesis at all, because dying, death and grieving are a central part of life for most Māori (Ngata, 2005; New Zealand Nurses' Organisation, 2006a). On the other hand, death is a taboo subject for many Chinese people who believe that it is bad luck even to mention the word (Schwass, 2005). In addition, it cannot be assumed that all members of the same culture have the same beliefs and attitudes. Therefore, this chapter should be read as a general overview that does not attend to the particularities of individual experience.

Furthermore, much of the earlier literature referred to was written in the late 1950s through to the 1970s, and as such may best be understood as the constructions of a time when a Western perspective was dominant. However, more recent works such as that of Seale (2000), Long (2004) and Kellehear (2007) incorporate cross-cultural perspectives, in an attempt to draw attention to, and increase awareness of, cultural diversity. In New Zealand, historical attitudes to death and dying as well

as the ways in which we care for people with a terminal illness have been challenged as there has been a gradual shift away from a monocultural perspective, to an increased awareness and acceptance of bicultural and multicultural traditions (de Bres, 2005). Local research with a multicultural focus is limited, however the Funeral Directors Association recently commissioned the book *Last Words* (Schwass, 2005), in recognition of the diverse ways that New Zealanders understand and approach death and dying, providing insight into the beliefs and practices of more than thirty different ethnic, cultural and religious groups.

Summary

The preceding overview of death and dying highlights, from a Western perspective, how our attitudes, expectations and behaviours are an amalgam of what has gone before. Since prehistoric times dying has progressed from being an event experienced by the whole community, to a family-oriented affair, to eventually becoming a private, professionalised experience. It has variously been argued that the contemporary difficulties experienced in discussing death and dying may be attributed to personal characteristics, an existential drive for preservation of life, societal changes, medicalisation and technological advancement, and changing demographics and epidemiology. The fact remains however, that in the absence of open discussion, it is difficult to elicit people's complex needs and preferences for care and to plan accordingly. This is an important issue for researchers, health professionals and lay people alike when trying to understand and improve the experience of care at the end of life.

However, the following chapter traces the recent emergence of a “death movement” committed to finding ways to achieve this goal.

Chapter Three:
Towards a ‘new’ way of caring

“The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal”

Peabody (1927)

Chapter Three begins by looking back to the late 1950s, when attitudes towards death began to gather momentum as a topic of psychological interest. At the same time, other fields, such as medical sociology, anthropology and nursing, were carrying out their own studies, all with the overarching desire to learn more about dying and death. These early works generated intense interest, leading to the creation of a multidisciplinary area of academic enquiry known as thanatology, the study of death and dying. This research, which peaked in the 1970s and again in the 1990s (Neimeyer, Wittkowski & Moser, 2004), as well as concerned lay people, increasingly challenged the care received by people who were nearing the end of life. As a result, new models of care have emerged, which form the basis of the discussion in this chapter. The following review considers EOL care primarily from the perspective of older people, and concludes by looking at the current New Zealand situation, and rural EOL care, thereby providing the particular context for this study.

Reviving death

DeSpelder & Strickland (2005) cite Herman Feifel's book, "*The Meaning of Death*", written in 1959, as the catalyst for the contemporary interest in death and dying within psychology. Feifel's book grew out of a symposium entitled "*The concept of death and its relation to behaviour*", which brought together a growing number of concerned professionals who had observed a lack of interest in, and information about, dying and death and the effect that had on the care of dying patients. In that same year, Feifel was told, "the one thing you never do is discuss death with a patient" (Feifel, 1990, p.538). However, less than forty years later, there had been such an explosion of studies in the field that Walter (1994)

suggested that there had been a revival of death. This continues to the present day, according to a meta-analysis of palliative and hospice care literature by Tieman, Sladek & Currow (2008). Their analysis found that between 1970 and 2005 the proportion of all Ovid Medline publications relating to palliative and hospice care rose from 0.08% to 0.38% of the literature. By the same year one in every 122 clinical trials published in the literature as a whole was in hospice or palliative care, which represented a growth rate 1.4 times that of the corresponding general literature.

The thanatological literature was spear-headed by pioneering books written on subjects such as the organisation of dying in hospitals (Glaser & Strauss, 1966), the psychological adjustments dying people make (Kübler-Ross, 1969), and terminal illness from a psychiatric point of view (Weisman, 1972). Journals such as *Omega*, *Death Education*, which is now called *Death Studies*, and the *Journal of Thanatology* appeared, as well as scientific and professional associations all concerned with death and dying. Universities introduced workshops and courses on dying, death and mourning and self-help and lay groups began to emerge. By 1967, Dame Cicely Saunders had established modern hospice care in England.

Several factors contributed to the revival in interest in dying and death. Firstly, concerned health professionals were becoming critical of how mainstream medicine treated dying people. Secondly, lay people wanted to reclaim some control of the dying process. Finally, increased media coverage of violent deaths and raised awareness of ethical issues, especially with regard to prolonging life, was prompting people to think more critically about their own expectations and

wishes (Leming and Dickinson, 2007). Walter (1994) argues that the revival indicates a postmodern reaction to the incongruity between the private and the public spheres. Professional and commercial interest in managing death and dying, for example in medicine, public health, funeral practices and the media, had become impersonal, to the extent that “private experience and public discourse do not tally” (p.23). Thus, according to Walter, a driving force behind the ‘revival’ was the need to incorporate a more personalised approach to care of dying and bereaved people. One of the reasons why such an approach had become necessary was because the way in which people were dying was changing.

“Terminal illness”: a new phenomenon

Population ageing

As mentioned in the last chapter, the age profile for dying people has radically changed over the course of the last century. To recap, this is mostly due to socio-economic and health factors such as the decreased incidence of childhood or early life deaths. In addition, public health and diets have improved (McNamara, 2001), and there has been no world war in almost seventy years. By the second decade of this century, the effects of the post-war baby boom will add to New Zealand’s ageing population (Dunstan & Thomson, 2006). With people living longer, the proportion of people living beyond the age of sixty-five is increasing. The number of over sixty-five year olds has doubled since 1970 (Dunstan & Thomson) and currently in New Zealand, around 12% of the population is over the age of 65. However, it is estimated that by the year 2051 this will rise to over 25% of the population (Ministry of Health, 2002).

Dying as a process

Not only is dying becoming a feature of old age in the developed world, people are dying more slowly (Walter, 1994) of degenerative diseases such as heart disease, respiratory diseases, cancer and dementia. In addition, many older people suffer from comorbidity. In other words, they have more than one chronic illness that affects their quality of life. This means that there may be long periods of illness before death with a person suffering, dependent on others and aware that they are 'terminal' or going to die (Seale, 2000). Furthermore, improved medical technology is available to support and extend the lives of those who are ill (McNamara, 2001). Because people are taking longer to die, they have had to learn a different way of dying (Walter, 1994). In addition, others have had to learn a new way of caring.

Living with an illness that is incurable is a living-dying experience, during which patients and their families fluctuate between denial and acceptance as circumstances and their responses to circumstances change (DeSpelder & Strickland, 2005). Weisman (1972) describes this as 'middle knowledge', when families and patients seek a balance between sustaining hope and acknowledging reality. Thus, how someone with a terminal illness understands dying and death, including when and where his or her life might end becomes important (McNamara, 1998). Furthermore, being able to make decisions about their own care greatly influences their experience and quality of life, something that is particularly relevant in the current climate of individualism and patient-centred care.

Hospitalisation of death

Going back a step in time, by the middle of the twentieth century, care of dying people had devolved to the experts, the medical profession, who generally viewed death as a failure. This is a notion which, according to Teno, Field & Byock (2001), persists in contemporary healthcare culture. In general, doctors and specialists continued medical intervention in the hope of effecting a cure, withholding information of impending death, supposedly in the best interests of the patient, who was a ‘problem to be solved’ (Nuland, 1994). According to Clark, cancer deaths, particularly, exemplified medicalised ‘modern death’ as “heroic and scientific struggles against the forces of illness and disease” (1998, p. 45). Inevitably, the over reliance on technology and medical procedures and the physician-focused approach was criticised, especially with respect to people with a terminal illness. Out of this socio-political climate, motivated by an overarching aim to improve quality of care and in turn, quality of life, hospice care emerged.

Hospice

The word hospice refers to a special kind of hospitality shown to guests or strangers, used in the 4th century by a Roman matron, Fabiola, to describe the Christian charity she afforded the destitute and the sick (Saunders, 2000). Her work inspired the formation of more hospices, which, although not specifically for dying people, provided material and spiritual help, and care, until they died. Centuries later, in the 1900s the word resurfaced, to describe the safe havens where incurable patients, shunned by hospitals because they were considered medical failures, received care. Then, history appeared to repeat itself in the 1960s

and 1970s when modern hospice care emerged as part of a broad social movement critical of the technological and clinical hospital care of dying people.

The foundation of the modern hospice movement is generally attributed to the pioneering work of Cicely Saunders, which resulted in the opening of St Christopher's Hospice in England in 1967. However, Clark makes the observation that this event more correctly represents "the *outcome* of ideas and strategies developed over the preceding decade, in which can be located the essential characteristics of the subsequent hospice movement" (1998, p.44). That said, the watchwords of St Christopher's are:

"You matter because you are you,
and you matter to the end of your life.
We will do all we can not only to help you die peacefully,
But also to live until you die", (Saunders, 2000).

Thus, in contrast to the prevailing medical model, which emphasised technological intervention in the fight against disease, the hospice pioneers regarded death as a normal and natural part of life, with an emphasis on care not cure, and quality not quantity of life. This therefore, was the beginning of care for dying people that attended to pain management, social, psychological and spiritual matters as well as disease symptoms; it was both the "science and the art of caring for patients with advanced disease" (Clark, 2007, p. 102). While in the early days, hospice care was almost exclusively for terminal cancer inpatients, its principles gradually transferred to other settings in the community. This included hospitals and homes, as a 'concept of care' for people in the end-stages of any progressive disease (Twycross, 2007), albeit under the guise of specialist palliative care. However, the

majority of hospice patients are still cancer patients, despite the call to change this (Addington-Hall, Fakhoury & McCarthy, 1998; The British Psychological Society, 2008).

Hospice in New Zealand

Modern hospice arrived in New Zealand thirty years ago, with the establishment of St Josephs, now called Mercy Hospice, in Auckland in 1979 (Latta, 2007).

Local services followed, funded within each community and supported by volunteers wanting holistic care for adults with terminal cancer, and eventually a national body was established in 1985. Today this body, known as Hospice New Zealand, “is actively involved in research and education, workforce development, establishing standards of healthcare, providing information and advice to hospices, stakeholders and to the general public and helping and supporting hospices nationwide” (Hospice New Zealand, 2005). Currently there are 37 hospice programs nationwide, 19 of which provide in-patient beds. Between 2007 and 2008, almost eleven thousand patients accessed hospice services, approximately 90% of whom have cancer (MacLeod, 2008).

Challenges to Hospice care

Given that the hospice movement grew out of a widespread dissatisfaction with the way that mainstream medicine cared for people with a terminal illness, one of the criticisms of hospice care is that it has now become part of the “vast cultural system of biomedicine” (McNamara, 1998, p. 171). Both Crossley (2000a) and McNamara (1998, 2001) argue that hospice care has joined the mainstream in terms of providing specialist management and control. While this may be so, my own experience of hospice care is that placing patients and their family at the

centre of their own care, acknowledging them as people with unique circumstances and needs remains a key difference that distinguishes hospice care from mainstream medical care. In addition, the empathy and compassion shown by hospice staff provides a balance to the acute hospital setting.

Furthermore, in New Zealand, hospices have to compete under market conditions, on a contract basis, for government funding, via their local District Health Boards. To do this they must demonstrate competence and accountability within the current healthcare system. Hospice care in New Zealand has grown so rapidly that public donations alone cannot cover the services they provide. In 2007 for example, 38% of New Zealanders who died utilised hospice services free of charge (Hospice New Zealand, 2007). That said however, the increased uptake and reliance on hospice care reinforces the notion that only specialists such as hospice can provide proper palliative care (Murray, et al., 2008).

Palliative Care

Palliative care as a medical specialty emerged from the Hospice movement (McNamara, 2004; Seale, 2000). New Zealand created its first Palliative Care Strategy in 2001 based on the guiding principles and definition provided by the WHO (n. d.),

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

- Affirm life and regard dying as a normal process;
- Neither hasten nor postpone death;
- Provide relief from pain and other distressing symptoms;
- Integrate the psychological and spiritual aspects of patient care;
- Offer a support system to help patients live as actively as possible until death;
- Offer a support system to help the family cope during the patient's illness and in their own bereavement;
- Use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, e.g. chemotherapy and radiotherapy, and includes those investigations needed to better understand and manage distressing clinical complications”.

Interestingly, in defining palliative care, the New Zealand Strategy states that, “palliative care integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life” (Ministry of Health, 2001, p.2). This reflects not only the hospice philosophy but also the Māori model of health (Durie, 1994).

Generalist and specialist palliative care

A distinction is usually drawn between generalist and specialist palliative care. For example, generalist care relates to the day-to-day care given by a person's

usual care provider, such as a GP or in the hospital. On the other hand, palliative care consultants and nursing specialists provide specialist care, often as part of a multidisciplinary team (National Council for Palliative Care, 2008). In this way, palliative care should be an element of all healthcare services, which can be integrated into patient care regardless of setting or diagnosis (Latta, 2007).

In line with international practice, New Zealand has its own example of funded palliative care in primary care, the Palliative Care Partnership (Stewart, et al. (2006). In the PCP, GPs, their practice nurses, specialist clinicians and other health providers work together to provide palliative care, in a model that appears to be working effectively, from the point of view of health professionals, as well as patients and family (McKinlay & McBain, 2007).

Specialist palliative care is more commonly associated with people who are nearing the end of life. For example, people deemed to have less than twelve months to live are admitted into the hospice programme, provided this service is available. However, patients often do not receive hospice care until the last 4 to 6 weeks of life (Addington-Hall & McCarthy, 1995). This may explain the public perception that if you are offered 'palliative care' that means you are dying, whereas in fact general palliative care is appropriate for people with both malignant and non-malignant diseases who will likely suffer over a long period of time (Latta, 2007).

One of the findings that consistently comes out of research is that palliative care should be offered earlier in the illness or dying trajectory than is often the case

(Nelson, 1999; Teno & Connor, 2009). This is especially relevant to older people with life-limiting illnesses who may have chronic, complex diseases with more unpredictable trajectories than malignant diseases (Currow & Hegarty, 2006). While they are the mostly likely to receive palliative care (Ministry of Health, 2002), it seems that the provision of palliative care for older people varies and leaves room for improvement, especially in institutional settings (Ministry of Health, 2001; Latta, 2007).

End-of-Life Care

Just as there is no one definition of palliative care, there is no commonly accepted definition of EOL care, thus EOL care and palliative care are often used interchangeably, or bracketed together. The National Council for Palliative Care (2008) states that EOL care incorporates both supportive and palliative care. This definition appears to be based on a narrow view of palliative care as providing only symptom control and pain relief. However, many definitions, such as the one used in the New Zealand Palliative Care Strategy (Ministry of Health, 2001) include social, emotional and spiritual support as well. It appears in general that EOL care and ‘specialist’ palliative care refer to the same thing. Similarly, EOL care is another way of describing terminal care; and of course, both of these terms raises the question of when a person is considered to be ‘terminal’ or near the end-of-life. Although the phrase ‘terminal care’ has gone out of vogue, it is still widely used and understood by members of the public (Seymour et al., 2005). These are complex definitional issues and indicative of the conflation that appears to exist between all three terms. I have used the term EOL care in this study because it is a broader term, encompassing all aspects of care provided at the end of life, which

for the purposes of this study I defined as being the last twelve months of life.

However, whatever the definition, the implicit aim is to support a person to die well or achieve a ‘good death’.

Dying well: good, well-managed, appropriate or just good enough?

Dying well

In the late Middle Ages in Western civilisation dying well was an art, guided by a series of manuscripts and woodcuts known as *ars moriendi*, (the art of dying). In effect, *ars moriendi* operated as a ‘DIY manual’ for clergy, doctors and lay people alike, informing dying people about what to expect; prescribing prayers, actions, and attitudes that would lead to a ‘good death’ and salvation; as well as providing guidelines as to how friends and family should behave at the deathbed. However, the 21st century equivalent for dying well, for many people, has come to mean achieving a good death through being able to control when and how they die (Kearl, 1996).

The good death

There are two commonly accepted meanings of the phrase ‘good death’ (Kellehear, 2007). The first, from the Greek, *eu thanatos*, literally means well or good death, but it can also mean a gentle and easy death. Clearly, this is where euthanasia originates, which, in contemporary times has come to signify control over death, through suicide or medical assistance. According to Kellehear, good death also refers to a death that has been well prepared for by the dying person in this instance deriving from the Greek *kalos thanatos* which means to die

beautifully in an ideal or exemplary way. The contemporary interpretation of a good death incorporates all of these explanations: dying an easy, painless, peaceful death; being able to make choices and have some control over the process; and dying at the right time with one's affairs in order.

In recent years, in keeping with the ideals of palliative care, many studies have focused on uncovering the 'actual' determinants of a good death. For example, Smith, (2000), Kehl, (2006), Kendall et al. (2007), and Hughes, Schumacher, Jacobs-Lawson & Arnold (2008) just to name a few, have all published articles about the concept of a good death. As result of talking with people dying of cancer, Kellehear (1990) listed five major features: an awareness of death, which is derived from others; making social adjustments and personal preparations; making public preparations such as legal wills; giving up formal employment duties and responsibilities; and making formal and informal farewells. Almost twenty years later, the National Health Service EOL care strategy stated that "although every individual may have a different idea about what would, for them, constitute a "good death", for many this would involve:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends (Department of Health, 2008, p.9)

To put it yet another way, according to Byock (1997) when asked to describe what would be a good death for them personally, people typically list what they want to

avoid, such as being abandoned, undignified or a burden and especially dying in pain.

However, despite the focus on finding a good death definition, the most meaningful conclusion to date is that it is a complex concept that incorporates many diverse points of view. For example, a hospice good death demands awareness and acceptance of approaching death. Yet, for some individuals closed awareness, evidenced through maintaining hope until the very end with a fighting spirit, may epitomise good death for them and be characteristic of the way that person lived their life. A medical good death may occur when doctors feel they have done everything possible to effect a cure or have provided adequate pain control.

A good death from a human development point of view might mean quietly slipping away in old age, with your personal affairs in order, or “having all your ducks in a row” as an acquaintance that recently died used to say. In addition, cultural perceptions of a good death differ (Hirai, Miyashita, Morita, Sanjo & Uchitomi, 2006; Noor et al., 2007), using for example, different cross-cultural ‘scripts’ (Long, 2004). Finally, another of the problems with the concept of a good death is the contemporary emphasis on easing pain and suffering. According to Illich (1976) and Seale (1998) this encourages the view everyone has a right to expect a pain-free existence and in this way humans lose their capacity to ‘perform’ suffering by accepting it as an inevitable part of life.

Alternative ways of talking about dying well

Over time, as this complexity has become better understood, different terms have crept into the dying discourse. For example, Weisman's (1972) notion of an 'appropriate death', which is the kind of death a person would have wanted, had they been able to choose, given the available resources, reflects the Western notion of individualism, or personal autonomy whereby people expect to make their own choices about how they will die (Seale, 2004). In contrast, Pattinson's (1977) idea of an appropriate death involves the family's wishes as well, which is more likely to resonate within cultures that understand death as a collective experience. More recently, Kellehear describes a contemporary good death in terms of management, "A well-managed death is a partnership between dying people and their professional services and not simply a comment of how well a person dies medically or psychologically" (2007, p.165). Finally, in a critique of the way that hospice care frames dying, McNamara argues that, despite the best of intentions, good deaths for patients are often just not possible and that practitioners now accept "a good enough ethic" (2004, p.934). Similarly, given her observations of severely unbounded and confused bodies, Lawton's (2000) study of hospice care questions whether, in the end, hoping for a good or dignified death is even realistic.

Place of death

Studies of where people die form a large part of the good death literature, looking for example at predictors for place of death (Murray, Fiset, Young & Kryworuchko, 2009), preferred place of death (Thomas, Morris & Clark (2004; Stajduhar, Allan, Cohen & Heyland, 2008), preferred place of death and of care

(Agar et al. 2008), as well as actual place of death (Gomes & Higginson, 2008). New Zealand's Ministry of Health no longer extracts data on the actual place of death (Hipkiss, 2009, personal communication, April 21, 2009) and there are few local studies on this subject, therefore the following section relies mainly on international information. However, this is likely to reflect experience in New Zealand, given for example that the fact that most deaths occur in hospital seems to be an unchanging feature of all developed countries (Constantini, 2008).

This is despite current research which suggests that most people would prefer to be cared for at home, although older people do not want to die alone (Department of Health, 2008). This latter point is worthy of future consideration, given demographic projections for large increases in the numbers of 'couple without children' families and one-person households in New Zealand in the future (Dunstan & Thomson, 2006). While most people would prefer not to die in an institution, this is where they do die, with increasing numbers of older people dying in residential care (Gomes & Higginson, 2008). In New Zealand, it is common practice for older people to be transferred from specialist settings to aged care facilities for continuing care (Ministry of Health, 2003). It appears then that a disparity exists between where people would choose to die and where they actually die.

While many studies state that being able to choose where they will die is important for dying people, Steinhauser et al. (2000) suggest that this is not always so, and that freedom from pain at the time of death is more important. This is understandable, because although people begin with a clear idea of where they

wish to be cared for, this decision often changes as care needs change and death becomes closer (McCall & Rice, 2005; Department of Health, 2008). This may be due to many things. For example, difficulties may arise for carers; the security of a medical setting may become preferable; people adapt to hospital or residential care; and sometimes unforeseen emergencies arise for which carers may feel unprepared. These fluctuations in need can be difficult for the patient, family and professionals to manage, which is when a patient centred approach can assist with decision making. Obviously then, the social determinants regarding place of death are complex, just as they are for a good death. However, all of the above presupposes that choices can be made because services are available and accessible. This may not always be the case for rural people.

Dying in rural New Zealand

The traditional rural death (DeSpelder & Strickland, 2005) is probably what most people, who are not dying, think of as a good death: at home, surrounded by family and friends. However as the research above shows, this does not happen as often as we think. In addition, McNaught's (2002) study showed that dying at home did not rank highly on a list of factors for dying well. Similarly, Gott, Seymour, Bellamy, Clark & Ahmedzai (2004) found that although older people wanted friends and family around them when they died this did not necessarily mean they wanted to die at home. These findings appear to contradict the palliative care ethos that supports dying at home as implicitly more desirable than institutional death. It is also counter to several government strategies that underpin contemporary healthcare in New Zealand. Dying people and their families may not be directly aware of the government strategies that inform their care. However,

as well as the Palliative Care Strategy (Ministry of Health, 2001) which informs of EOL care, the following social policies also guide the service provision of care for older people in New Zealand, of whom rural people are a ‘subnational’ group consistently identified as needing particular attention.

Social policy

The Positive Ageing Strategy (Ministry of Social Development, 2001) recognises the need to support older people in maintaining health and independence.

Focusing on active engagement and good health as indicators of positive ageing, the strategy aims to change negative perceptions of ageing that position older people as gradually withdrawing or disengaging from society due to chronic debilitating illness or incurable disease (Boston & Davey, 2006). In particular, Goal Five of the Positive Ageing Strategy is that people feel “safe and secure and can age in place” (Ministry of Social Development), meaning that older people should have the choice and the opportunity to choose where they live and should be supported in their wish to remain independent and ‘at home’ for as long as possible.

In accord with these aims, the vision of the Health of Older People Strategy is that “Older people participate to their fullest ability in decisions about their health and wellbeing and in family, whanau and community life. They are supported in this by co-ordinated and responsive health and disability support programmes”

(Ministry of Health, 2002). Finally, The New Zealand Carers’ Strategy and Five Year Action Plan (Ministry of Social Development, 2008) is a recent initiative that is more directly applicable to EOL care. While this is a step in the right direction,

with general guidelines that could benefit the carers of dying people, the strategy focuses mainly on long term carers of people with disabilities. There is nothing specific for carers of someone with a terminal illness, especially older carers, who are often women, caring for a spouse, older relative, or friend. This care may be provided for only a few months, weeks or even days, however it is typically intensive, both physically and emotionally.

Living and dying in a rural setting

It is against this background of social policy that older people with a terminal illness make the transition into specialist palliative care. Having been assisted to remain in their own homes as long as possible, it does seem likely that they would want to be cared for in their own home, although this cannot be assumed.

Although some older people make the conscious move away from smaller rural areas to be closer to better, or more specialised, medical care, others choose to remain where their roots and friends are; others simply cannot afford, financially, to move. On the other hand, according to Davis & Bartlett's (2008) review of rural Australian ageing, which resonates with New Zealand experience, older people retire to rural areas for the lifestyle and scenery, to reduce the cost of living, and with the expectation that smaller communities are more cohesive and supportive. Unfortunately these perceived benefits are counteracted by limited resources and services, especially with regard to healthcare.

This leads to the question, what kind of services and resources can an older person, living and dying in a rural setting in New Zealand expect to receive? How likely are they to achieve an appropriate or well-managed death, or even one that

is good enough? To my knowledge there has been no study of rural EOL care previously undertaken in New Zealand. Therefore, the following section draws on international literature, which in itself is meagre in comparison to urban studies. Although specific to rural settings, in many ways the findings here echo the general literature on EOL and palliative care.

Services and resources: access and limitations

In their study of rural UK community hospitals, Payne et al. (2001) found that although these hospitals could be a good option for providing palliative care, services and resources varied widely. This also appears to apply to the provision of hospice care in New Zealand. According to the Palliative Care Strategy (2001) there are no hospices on the West Coast of the South Island, particular areas on the East Coast of the North Island, Wairau or Queenstown. In addition, some areas with hospices are run by volunteers, with no clinical services. The areas with no access to hospice care rely on hospitals and primary care providers for care. For example, people dying in rural areas are generally dependent on GPs, primary health care nurses, and district nursing services which are often in short supply. Similarly, Casey, Moscovice, Virnig & Durham (2005) discuss the problems of staff shortages in rural areas, placing hospice workers at risk of burn-out. In addition staff experience difficulty maintaining professional boundaries between work and personal lives when living in a small community. According to Dunham, Bolden & Kvale (2003) caring for someone that you know on a personal basis is especially emotionally draining.

Caregiving burden

In this respect, there needs to be more support and training for nurses and other palliative care providers working in rural areas (Wilson et al., 2006). This need for support also extends to family caregivers. Providing physical care and witnessing the physical problems of their loved ones are the most frequently reported stressful experiences for family carers (Wilkes & White, 2005). Rural women especially, tend to bear the brunt of the caregiving (Crosato & Leipert, 2006). Apart from the physical and emotional burden of caring, Crosato and Leipert also cite limited access to appropriate services, having to travel long distances, and culturally incongruent care as particular issues for EOL care in a rural setting.

In an attempt to address the issue of culturally appropriate care in New Zealand, a mobile Māori nursing service that specialises in oncology and palliative care for Māori clients has recently started in the Western Bay of Plenty (New Zealand Nurses Organisation, 2006b). The aim of this service is to enable patients to remain at home, surrounded and supported by whanau. Many older rural people however do not have suitable social networks, family carers and other resources that allow them to remain at home, and therefore need community hospital or residential EOL care (Payne et al., 2001). Yet, even though caregivers may be committed and well-intentioned, the caring experience is challenging and exhausting (Wilkes & White, 2005).

Information, education and training

Much of the EOL care research considers better education, information sharing and training to be key areas for improved quality of care. This is also evident in

the rural literature. For example, Kelley, Habjan & Aegard, (2004) suggest that educating community-based health professionals improves the ability of rural areas to deliver palliative care. Wilkes, White & O’Riordan (2000) found that information sharing was one of the most important forms of support for families caring for sick relatives. Van Vorst et al.’s (2006) survey of health care personnel indicates a desire for ongoing training, reflecting the challenges of working in a changing medical field.

The variability of specialist rural palliative care services means that primary care providers play a key role in EOL care. However, Evans, Stone & Elwyn’s (2003) literature review of rural palliative care organisation and rural health professional’s views, found little information about GP’s perspectives and needs. Although not specifically a rural study, Walker & MacLeod (2005) sent questionnaires out to South Island GPs in New Zealand, the results of which identified an understanding of basic principles, but also highlighted important knowledge gaps, including not knowing the appropriate response to certain palliative care emergencies. Similarly, Mitchell’s (2002) review of GP care in general found that GPs tend to question their own ability to offer adequate palliative care, especially when faced with less common symptoms. However this changes with the support of a specialist team approach.

In summary, the rural EOL care literature focuses on three key areas: access to specialist EOL care services; support for family carers, and health professionals; and adequate information sharing, training and education for health professionals and informal carers. Just one study, which explored differences in attitudes toward

death and EOL decision-making (Gessert, Elliot & Peden-McAlpine, 2006), compared rural-urban differences so it cannot be categorically stated that rural experiences are better or worse than urban experiences, however it is generally accepted that there are more health services, which are more easily accessed in the major urban centres.

In addition, these studies demonstrate the diversity of rural lives and circumstances. Therefore it is a mistake to assume there is a 'universal' rural experience. This includes the assumption that all older people enjoy supportive social networks. Several of the articles suggest that the best way to overcome challenges in rural care is by forming collaborative and supportive partnerships between patients, their families and health professionals, which reflects the patient centred perspectives found in the general EOL care literature.

Summary

This chapter has traced the emergence of death and dying, from being taboo and hidden in hospitals, into a new field of academic enquiry and into daily experience. At the same time, changed dying trajectories have led to new ways of caring for dying people. Hospice care has evolved into the medical specialty, palliative care, which perceives dying as a natural process and promotes patient centred care. In a holistic approach, psychosocial and spiritual needs become as important as physical care, which focuses on pain relief. Patient choice and control are considered, as well as family wishes and needs, as part of the 'unit of care'. At the same time, 'home' has returned as the preferred place to die. All of which has been motivated by the aim of enabling people to die well.

The final section of this chapter considered rural EOL care, from the perspective of older people. However, there is a paucity of literature in this area in general, let alone from New Zealand. While we do tend to follow international health care models, especially from the UK and Canada, knowing something about older rural people would enhance future rural EOL care planning and the provision of quality care in New Zealand. This is especially important given that the population of older people in rural areas is projected to steadily increase in future years.

Therefore, this study asks the question:

“How do older people with a terminal illness, and their carers, experience end-of-life (EOL) care in a rural New Zealand setting?”

Chapter Four:

Methodology

“We are all storytellers and we live in a storied world”

(Murray, 1999)

Chapter Four begins with a discussion of how this project was conceived, including the reasons why certain choices were made with regard to the study design. This makes explicit the epistemological assumptions that underpin the study. The chapter concludes with a detailed examination of the method of data analysis.

The idea for this study germinated while I was helping to care for my father who was dying in the rural district in which this study takes place. I had no previous knowledge of how the medical system worked or how people died in the twenty-first century. The only thing I knew about Hospice was that it was where they sent you when there was no longer any hope. I did not know what palliative care was, or what the term meant. I coped by gleaning information and support from others in everyday conversations. Speaking with people who had had similar experiences guided me, and my family, through the process of my father's dying. Recognising that others faced similar issues and challenges, negotiating the dying process in an almost ad hoc manner, I wondered how the experiences of people like me, and families like mine could be utilised to improve end of life care for others.

One of the first assumptions I made regarding the study design was that lay people have a reservoir of valuable experience that is helpful and supportive for others, especially when facing something unknown. The following quote, from a doctor who survived cancer, supports this belief: "Through [sharing experiences], I realised that other patients could give me something unique which I could not obtain from my doctors or nurses, however caring" (Clement-Jones, 1985, p. 1022). On the other hand, I had felt like an 'outsider' during my father's dying,

with the choice and control that permeates contemporary health and palliative care discourses being diminished by a lack of informed 'expert' knowledge.

This feeling continued into the research process as I met with resistance because I was not an 'insider'. The mildest expression of this was the expressions of surprise that I was not a nurse or at least working within the field of palliative care. In an attempt to address this, I became a member of a Palliative Care Research Interest Group as well as attending a palliative care seminar for care assistants, developed by Hospice New Zealand. In summary then, one of the aims of the study was to bring the two 'camps', lay and expert, closer together by bringing some understanding into the academic arena of what the experience of EOL care was like for lay people. I hoped this would be useful for health professionals and service providers when planning EOL care in the future.

The last few decades have seen a change in medical focus from physician-centred care towards patient-centred care. A feature of this kind of care is that patients become active participants in their own care, rather than passive recipients (Laine & Davidoff, 1996). In New Zealand, the Code of Health and Disability Services Consumer's Rights reflects this shift by setting out ten rights that people have as health 'consumers', which must be followed by anyone providing any sort of health or disability service (Health and Disability Commissioner, n.d.).

Research supporting patient-centred care is more concerned with patient experiences, than, for example, results of the clinical outcome studies used in evidence-based medicine (Krahn & Naglie, 2008). As a result, there has been a

recent move towards incorporating patients' perspectives in research about themselves. However, despite the support for incorporating the views of palliative care 'service users' when designing services for them (Conner, Allport, Dixon & Somerville, 2008) a preliminary literature search regarding EOL care suggested that patients' and carers' perspectives are under-represented compared to the views of health professionals, and that rural perspectives in particular are noticeably lacking. This, and the assumption mentioned above, guided my decision to focus on lay perspectives as opposed to those of health professionals, such as GPs and hospital specialists.

Social constructionism

The preceding example of how medicine has gradually shifted from a physician-focused model of care to a more patient-centred model demonstrates how practices and perceptions can change over time. Similarly, what we consider is 'knowledge' changes as well. Thus, the way that people understand the world is culturally and historically relative (Gergen, 1985). This is one of the assumptions of social constructionism: a theoretical orientation that encompasses different approaches, grounded in similar assumptions, which people use to understand the world, and themselves. As well as the one already mentioned, other assumptions include the questioning of taken for granted knowledge, knowledge as a social process, and knowledge from negotiated understandings (Gergen, 1985).

Social constructionism offers another way of understanding the world. For example, the traditional, scientific approach in mainstream psychology has been to strip away social variables or confounds, in order to isolate discrete variables that cause fixed-for-all-time, universal effects. In contrast, social constructionists

advocate an approach that accommodates contextual variables, recognising that any knowledge is a partial, incomplete and situated view of the world (Denzin & Lincoln, 2005). This view underpins the thesis presented here.

Social constructionists assume that we gain knowledge through an understanding of social processes (Gergen, 1985). For example, as people interact, they construct knowledge between them. This interest in social interaction leads social constructionists to be primarily concerned with language, and in particular its performative nature, or what it does. Researchers working within the social constructionist paradigm utilise many different approaches, including discourse analysis, post-structuralist, rhetorical and postmodernist approaches (Crossley, 2000b). Narrative psychology, which recognises the central and constructive role played by language and informs the work undertaken here, is another of these approaches.

Narrative Psychology

According to Polkinghorne, (1988) what we 'do' is the proper object of study of human beings, not the 'things' that are typically studied in the natural sciences. In addition, he states that what we do is understood through the medium of language as, during the processes of talking and writing, people join everyday actions and events into episodes that provide a framework for understanding past events and planning future actions. At the same time, we interpret our actions and experience in terms of how they relate or connect to something or someone else, as well as their moral stance. This includes stories and narratives told to each other, or constructed together, and those handed down over time (Crossley,

2000b). Thus, we give meaning to our experience of time and personal actions through narrative. In this way, according to Crossley, narrative psychology assumes that people understand themselves, and others, through language.

Narrative analysis

Having accepted that narrative constructs human experience, the next question becomes how to unpack the meaning of an experience in all of its complexity and contextual detail. Polkinghorne (1988) suggests that one way of hearing the meaning of a story is through hermeneutic reasoning. Originally, an interpretive approach to understanding the meaning of (biblical) texts (Hughes & Sharrock, 1990), hermeneutics in psychology has become a way of studying and understanding, or interpreting human action. Hermeneutic methods are qualitative, as opposed to quantitative statistical techniques, using the same kind of linguistic processes that we use when constructing our own narratives to interpret the meaning of someone else's story. Therefore, in the first instance analysts need to understand what a narrative is. You would expect that we all know what a story is, but as Polkinghorne points out, the emplotment of events into a story is such an ordinary part of life that we usually do not attend to how we do it, only the reality that it produces.

What is a narrative?

Individuals construct narratives by selecting important events, and then sequentially organising or connecting them in a meaningful way for a particular audience (Riessman, 2008). Thus, a fundamental criterion of narrative is contingency; that is, whatever the content, events or ideas must be linked

consequentially. In this respect, narratives impose a meaningful pattern on what would otherwise be random and disconnected (Salmon, 2008). To put this another way, in the telling, by selecting or attending to certain events, thereby creating a plot, the experience becomes value-laden, or has meaning (Cronon, 1992).

Referring back to the earlier discussion of social constructionism, narratives are best understood as being composed for particular audiences at particular moments in history, drawing on taken-for-granted discourses and values embedded in a particular culture (Riessman). Consequently, narratives do not speak for themselves or provide a transparent view into the phenomenon under study. Therefore, when used for research purposes they require interpretation, (a hermeneutic approach) which can be accomplished in a number of ways depending on the objectives of the investigation.

In narrative analysis, in the first instance, the object of investigation is the story itself, which, in this project is first-person accounts by participants of their experiences of EOL care. The purpose of the analysis is to see how the participants order their experiences so that events and actions in their lives make sense. Therefore, the researcher examines the story, looking at how it is put together, looking for the linguistic and cultural resources it uses, and deciding how it persuades listeners that it is authentic. In other words, the researcher asks, “why was the story told *that way*?” (Riessman, 1993, p.2)

Different kinds of narrative analysis

There is more than one way to conduct a narrative analysis. In fact, the term actually refers to a diverse set of methods or ‘family’ of interpretive approaches

(Riessman, 2004). For example, Riessman (2008) describes three different approaches: thematic, structural, and dialogic or performance analysis. In addition each of these approaches could be applied at various levels: personal, interpersonal, positional and societal (Murray, 2000). Throughout this study, I have utilised a variety of these, depending on the point that I am trying to make at the time.

An overview of the analysis process

When conducting a narrative analysis, there is a multi-layered interpretive process at work. In the first instance, when telling their story narrators select what they want to say and what they do not want to say. Their stories, which are recollections of past events, are not neatly stored, intact, in the filing cabinet of their minds, ready to pull out in exactly the same form every time they are told. Rather, they are a selective re-presentation of an event or activity, narrated in a particular way at a particular time, with a particular purpose. In this way, in telling the story, narrators position themselves in a certain way to their audience (Murray, 2000). At the same time, depending on how the interview process is conducted and the researcher's point of view, the researcher's role as listener may also be considered part of the initial narration, which is then viewed as a co-construction (Riessman, 2008).

Once transcribed, the narrative is closely read, then analysed according to the method that the analyst thinks best fits the objectives of the study. In the next step, the researcher re-presents their interpretation of the original story in the form of another story to another audience. In this way, Riessman (2008) argues that the

researcher has not 'found' a narrative but rather, participated in its creation. Furthermore, the audience may, given enough information formulate their own interpretation of the original story. The whole exercise therefore, becomes a series of constructions or "a story about a story about a story about a story, ad infinitum" (Gelfand, Raspa, Briller & Schim, 2005, p. xxiii). In this respect, it appears that there is no single, fixed version of truth for a particular event.

However, Crossley (2000b, p.40) argues that narrative analysis "has a 'topical' or 'substantive' orientation to it", which in fact, produces narratives that are "best characterized as 'old-fashioned' or 'realist'" (p.41). In addition, Sarbin and Kitsuse (1994, p. 8) state that:

"even though ordinary folk are more likely to be realists, having reified the constructions acquired through experience or authority, they nonetheless report their constructions of the world through the use of stories. What they report are their social experiences, the making of which follow well-established narrative plots".

These observations highlight a dilemma I faced when choosing which type of narrative analysis to use for my study. This, actually, was a 'crisis' point for me. I felt like I was caught between two paradigms. Personally, I was aligned more towards social constructionism and my interest in what language does; yet morally I felt that to honour the women's stories, which were very 'real' to them, their experiences had to be presented in a realist paradigm that was meaningful and acceptable to them. In the end, the reason for taking a more 'realist' approach was political, relating back to one of the original aims of the study. In my initial

information to the participants, I had implied that this work could be presented to people who are responsible for planning EOL care. Therefore, I had a responsibility to analyse and re-present the stories in a way that would most likely be influential in that context. While it might seem that I have done an about turn with regard to where this work sits epistemologically, I am comfortable that it remains under the umbrella of social constructionism, albeit at the weaker end of the social constructionist continuum (Moghaddam, 2005).

The researcher as a *bricoleur*

In light of the preceding discussion, I truly feel like a *bricoleur*, or quilt maker (Denzin & Lincoln, 2005), having taken bits and pieces from here and there to stitch together a quilt that tells a story, which has taken on a life of its own as the pieces have melded together. I have borrowed from different disciplines such as sociology, anthropology, medicine and nursing as well as psychology and incorporated historical, cultural and social influences, as well as individual differences. I have cut and pasted the women's stories to present a particular argument. Moreover, I have mixed my methods in order to do this. In this way, Appendix I, at the end of the thesis symbolises my interpretation of the women's stories. In other words, their stories became my story; the result of re-working their words into what I hope is a respectful and authentic re-presentation of what they wanted to tell me, knowing that it would ultimately reach a wider audience.

Chapter Five:

Method

*“...researchers must be free to develop and apply methods
that are appropriate for finding answers to the research questions
under consideration”*

(Chamberlain, 2000)

The following chapter outlines the research process, beginning with a description of the participants. A detailed explanation of the procedures used follows, including how and why the study changed from its original aim of talking only to people with a terminal illness, to include people who had cared for someone with a terminal illness within the last eighteen months. The chapter concludes with an explanation of the analysis process.

Participants

The participants invited to take part in the study were from a rural New Zealand district with a population of approximately 20,000 people. In the absence of an internationally recognised definition of a 'rural' area (Statistics New Zealand, 2008b) I used Statistics New Zealand's (2006) definitions to classify the smaller townships as rural, based on having a population between 300 and 999 people. The one large town in the district has a population of around 12,000 people, giving it a secondary urban classification.

However, the residents of this town, especially those from older cohorts, tend to self-identify as living in a rural area, given that the town itself has historically been the service hub for surrounding rural districts. In this respect, the overall definition of rural may be considered problematic, however the town residents do live more than 100 kilometres from the nearest hospital that offers specialist medical care. The median age of residents aged over sixty-five in this district is currently around twenty per cent, compared to the national average of just over twelve per cent. By 2031, it is predicted that more than a third of the population for this area will be over the age of sixty-five (Dunstan & Thomson, 2006).

Seven people took part in the study, all of whom were women and carers. One man had shown an interest in taking part, however he died before an interview could be arranged.

Specifying the varying caring roles proved problematic, because of the difficulties around defining care. Drawing from both the literature and information supplied by the participants, I used the following taxonomy for the purposes of this study. In everyday talk, there is a distinction between formal carers who work under the auspices of a health provider and are paid and informal carers who have no umbrella organisation and may be paid or not. These people may or may not have formal training or qualifications related to 'caring'. There is a tendency to call people who work in a rest home, with or without formal qualifications, "care assistants". On the other hand, health professionals are typically people trained to provide care in the public arena. They are not generally referred to as 'carers'. This raises the question: does that mean they do not provide care? The perception that different people provide different kinds of care is an issue for discussion in the next chapter.

Based on the above, two of the women, Catherine and Janet, were informal, unpaid carers of Graham and Paul who had died within the last eighteen months. One woman, Lillian, had been a paid informal carer of a gentleman, and earlier his wife. Three formal, paid carers responded, Neroli, Tavae and Jill, as well as one rest home owner, Diane. Two of the formal carers were enrolled nurses; the other was a care assistant. The trained formal carers could also be considered health professionals in that they are paid to provide care for members of the public. I have deliberately omitted further detail about their personal circumstances for reasons of confidentiality. Similarly, all names used in this study are pseudonyms in order to protect the participants' anonymity.

Responding to the ethnicity question from the 2006 census, five of the participants identified as NZ European, one as Samoan and one participant identified as both NZ

European and Maori. All of the participants were over the age of forty, with only one being under fifty. Almost half (43%) of the participants were over seventy years old. For a more comprehensive analysis of the demographic data, see Appendix G.

Procedure

Ethics

Prior to receiving ethical approval from the Lower South Regional Ethics Committee, I spoke with local health professionals about the study and obtained permission to place community notices on their premises. For example, I spoke with GPs, the Community Services Co-ordinator and the Nursing Co-ordinator at the hospital, the assistant Manager at the only rest home providing hospital care and the Cancer Society Client Co-ordinator. In addition, I consulted with, and obtained letters of support for the study, from a representative of the local Runanga, the administrator of the Research Consultation Committee for the local Iwi and the specialist palliative care provider in the area.

Recruitment

Having obtained ethical approval, community notices outlining the research and inviting expressions of interest to participate in the study (see Appendix A) were placed in public areas such as the local hospital, a rest home with hospital accreditation, medical centres and doctors' surgeries, the public library, and the Cancer Society meeting room. As well as the larger notices, smaller versions were placed nearby in document holders so that interested people with no pen or paper available to take down the contact details of the researchers had information to take away. Taking the information with them also

allowed people more time to carefully consider the study and make a better-informed decision to respond.

At the same time, I intended publishing an article outlining the rationale and aims of the project, which included the researchers' contact details, in the local weekly newspaper, which is delivered to all households in the district free of charge. However, for reasons beyond my control, the article was not published. While waiting for the article to appear in the newspaper, one person contacted the researcher expressing an interest in the study. This person was however, a person with experience of caring for older people with a terminal illness, and was therefore ineligible for the study.

The publishing delay as well as the lack of response from potential participants prompted a change in the study's focus. Therefore, I obtained ethical approval for a revised study that included people who had cared for a person with a terminal illness within the last eighteen months. The timeframe of eighteen months was significant because a new palliative care service had started in the district during this time. Any stories relating to care before that time may therefore have become outdated in terms of suggestions for improving future care.

Revised community notices (see Appendix B) were distributed and an accordingly revised article was published twice in the local free newspaper (see Appendix C). The newspaper article was also published three times in the local daily newspaper, which is not free, nor is it delivered to all households.

Four people responded, by telephone, to the articles in the free newspaper. One person expressed an interest in taking part in the study as the result of a conversation with me and one of the participants who had already completed an interview referred one person to me. I sent information letters (see Appendix D) to all potential participants inviting them to take part in the study. I also contacted the person who had initially responded to the original community notice, to see if she was still interested and as a result sent her an information letter.

Having allowed time for participants to read the information letters, I contacted everyone again to see if they were still interested. Everyone remained committed to the study and interview times were organised. Although each participant was offered the opportunity to have the interview conducted in a 'neutral' meeting place, they all chose their own homes apart from the rest home manager who was interviewed in her office. I also took morning or afternoon tea with me, which helped to create a more 'natural', informal atmosphere. Before taking part in the interviews, the participants were given the opportunity to ask any further questions relating to the study and then to complete the consent form (Appendix E). They also supplied demographic information at this time (see Appendix F). During the week after the interview, the participants were sent a hand written thank-you card for participating in the study. All participants requested a summary of the results at the conclusion of the study.

Six of the participants agreed to have the interview recorded. One participant preferred to have notes taken only. After transcription, they were presented to the participant for approval. The participant made written amendments, which we discussed at a second meeting. The notes were re-typed, including additional comments from the second

meeting, and presented to the participant who made some final adjustments. The remaining five participants were invited to read the transcripts of their interview and to suggest changes or deletions before the results were written up. Three participants chose to do so, including the participant whose interview was not recorded. However, by the time transcription was complete one of the participants changed her mind and decided she would prefer not to read her transcript. The one participant who read her transcript did not wish to make any changes.

Interviews

I chose to conduct face-to-face interviews because of the sensitive nature of the topic being researched. I thought this method would be more appropriate and conducive to eliciting rich narratives than, for example, public disclosure in focus groups. I began each interview with the intention of facilitating a conversational-style process, as opposed to adhering to a strict question and answer guideline. The reason for using this method was to approximate everyday information exchange and support between lay carers and because I was interested in the complexity and subjectivity that is characteristic of non-structured interviews. To this end, rules of everyday conversation applied, including turn-taking, relevance, and entrance and exit talk (Riessman, 2008).

Although I prepared an interview guide as part of the process for ethical approval, which was available to use for prompts if conversation stalled, in most interviews the pre-prepared questions were generally answered during the course of the conversations, without having to be introduced by me. I welcomed any digressions by the participants because not only did the ensuing discussions provide detailed responses, but these asides sometimes raised important issues that I had not considered when preparing the initial interview guidelines. Therefore, the digital recorder ran for the entire interview,

unless I was specifically asked by a participant to turn it off. This happened once, when a friend came to the door.

The participants spoke about their own personal experiences, and as surrogates, interpreting what they believed care was like for the people they had cared for. In addition, because I had recently experienced caring for someone with a terminal illness, recounting my own experiences gave me some ‘insider’ credibility and provided a means for opening up further discussion. At times, the conversations flowed spontaneously, producing insightful narratives. At other times however, the conversation was somewhat stilted, more or less following the question and answer format that I had wanted to avoid. This was particularly evident in the earlier interviews and may be indicative of my interviewing technique, which became more refined with each successive interview. Despite making a conscious effort not to present myself as being in a position of power, I think this was inevitable due to my role as an academic researcher. I certainly had more control over the process than the participants had. Furthermore, it is likely that the participants volunteered for the study in the hope that I had access to people with the power to make changes in the future. Therefore, despite my best intentions, conversations cannot be viewed as an exchange between equals.

Analysis

Before transcribing the interviews, I listened to each one several times. This allowed me to immerse myself fully in the data, as I developed a feel for emerging and significant themes. This was an interpretive approach, in contrast to more positivistic methods that identify themes *a priori* to generate coding guidelines, or categorise texts on the basis of recurring words or phrases or the number of times certain topics appear. Later, when I

read the texts, I ‘heard’ the conversations as they originally sounded, which influenced the interpretation process.

Next, I personally transcribed each interview, in its entirety, adhering as closely as possible to the recording. This means that the data has not been ‘cleaned up’ (Riessman, 1993) and that my questions and responses, including affirmations and interruptions are included. It was at this stage that I realised that although there were some positive and uplifting stories, the tone in many of the interviews was quite negative and critical. I will discuss why I think this was in the next chapter. I adapted the transcription conventions (see Appendix H) from Silverman (2004), with some modifications and additions. The rationale for the conventions used was twofold. Firstly, I wanted to highlight the interactive process between narrator and listener. Secondly, I wanted to present the text in a way that provided enough contextual background to give some clue as to the emotional content of the conversation yet was not so complicated that it lost its fluency, thereby making it difficult for the reader to follow the storyline.

I then read the transcripts several times, noting down passages of talk that spoke to similar issues across all of the participants. At this stage, I noticed that the discussions of the same issues both converged and diverged. Sometimes, an individual would contradict herself when talking about the same topic. Therefore, when it came to presenting the findings I organised them into themes while at the same time highlighting differences and similarities. I did this in order to emphasise the complexity that arises from different contextual backgrounds, between individuals and over time. This is in contrast to a positivist approach, such as IPA or grounded theory whereby common

experiences are taken from the data and grouped together to reveal a 'universal' experience.

Having identified the narratives that I felt were significant, I began to 'write up' the results. However, it was not long before I felt that something was missing. As the researcher, it was my role to listen, interact, and after a period of analysis re-present the women's stories in an authentic, coherent form that would be meaningful for other audiences. Now however, I realised that somewhere in the thematic analysis, the stories had lost their coherence, their authenticity and their power. I had a dilemma. Should I proceed with an 'across-case' thematic analysis, or should I concentrate more fully on fewer stories, and keep them intact (Riessman, 2008)? For example, there were stories about particular events and specific characters that formed a coherent whole, describing or evaluating an action or sequence of events that had some consequence. These were examples of what Riessman (1993) would call narratives. Other pieces of text were simply short answer responses to questions that I had 'prepared earlier' as a result of reading the literature. I decided that these were what Riessman calls "other forms of discourse" (p.3) that, judging by their brevity, were less meaningful for the participants.

Therefore, at this point, I decided to concentrate on the narratives that touched me at the time of the interview, eliciting, for example, feelings of sadness, disbelief, sympathy and admiration. These stories had a distinctly performative aspect (Riessman, 2008), evidenced by a noticeable shift in engagement between narrator and listener. At the same time however, I have included excerpts from other participants in support or as counter-points, so that the results are a hybrid of thematic and dialogic narrative analysis (Riessman, 2008) using both a case study approach (Radley & Chamberlain,

2001) as well as a kind of comparative analysis found in grounded theory. This, I felt was the closest I could get to integrating and re-presenting the narratives across several levels (Murray, 2000). I acknowledge that this is an eclectic approach, taking on board Chamberlain's (2000) caution of the danger of being a 'charismatic' who draws on different methods unproblematically. However, I think that Denzin and Lincoln's (2005) explanation of the qualitative researcher as *bricoleur* is an apt metaphor for the methods I have used. Figure 1 is a diagrammatic representation of the entire process.

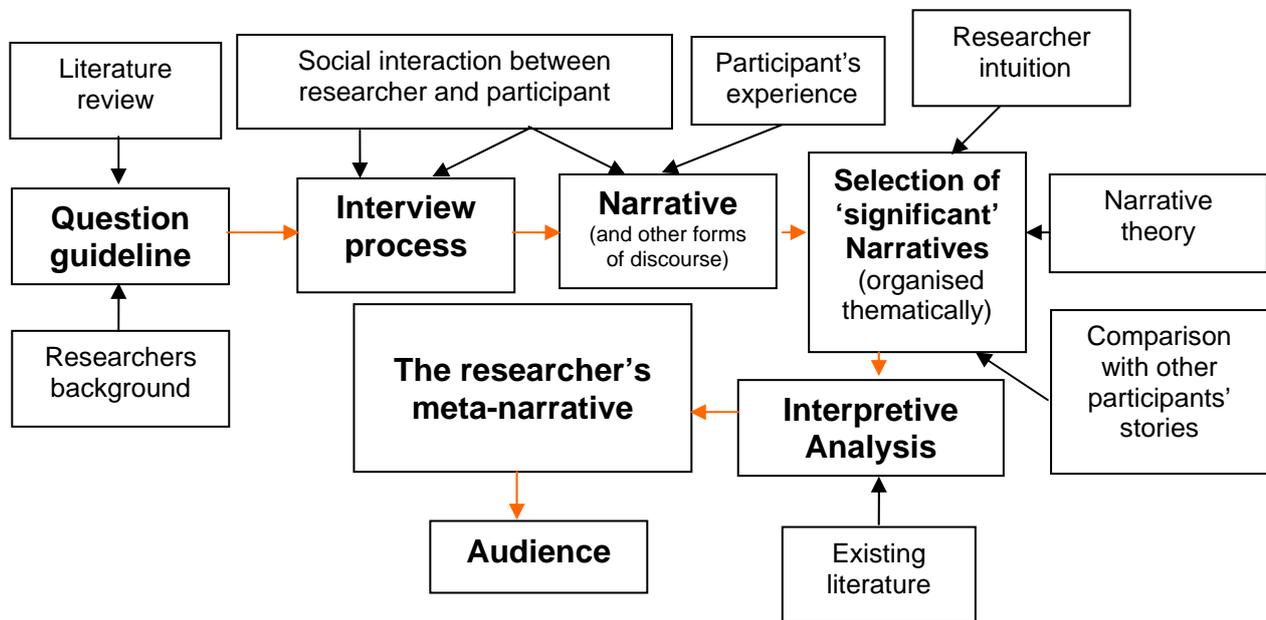


Figure 1. Constructing a meta-narrative as part of my thesis

In the next chapter, I present the results of my analysis and discuss my interpretation of what the participants told me about their experience of EOL care. These are the stories that have stayed with me long after the interviews were over. Furthermore, I suspect that the women will re-tell some of these stories over the years to come.

Chapter Six: Results and Discussion

“The patients certainly cannot be dismissed because they are not experts. Any one person can have as much understanding of death as any other”.

Young & Cullen (1996)

In this chapter, I present and discuss the findings of the study. These are the stories that ‘spoke’ to me, in the first instance, as a fellow carer and human being. The majority are poignant narratives, which were clearly meaningful to the participants, standing out from the body of the interviews because of their detail and structure, as well as the way in which they were narrated. However, re-creating the speech as written text loses the body language, the nuanced speech, and at times, the depth of emotion shown by the women, which is integral to the interpretation process. Therefore, in an attempt to provide some contextual detail, thereby enhancing understanding and appreciation, I have included descriptions and notations for readers (see Appendix H for the complete list of transcription conventions). At the same time, in some instances I have combined narratives on the same topic, by the same participant into a ‘composite’ narrative. This does not change the meaning or sequential features of the narrative, it merely removes repetition and some less relevant information (from my perspective) for the sake of brevity. Finally, to a certain extent readers will have to trust my intuition that these are significant narratives.

The chapter is organised via comparisons between the stories, as a way of highlighting the similarities and the differences that exist between just seven people talking about similar issues, but from quite different perspectives. At the same time, careful reading of the narratives indicates contradictory views from the same individual in some instances. This suggests two things. Firstly, as different issues become more salient during the dying process, perspectives change for that person. Secondly, it may indicate a shift in position that a particular participant adopts as the participant-researcher relationship changes and develops over the course of the interview. Each section is organised around a significant narrative, with excerpts from other participants. When this additional

material is not a narrative *per se* (Riessman, 2008) it serves to support or contradict the discussion.

Despite their different backgrounds, the participants agreed on two issues in particular. One was the significance of time: having time to get to know patients and form relationships; having time to sit and listen; having time to offer a comforting touch; in a nutshell, having time to care, ‘in an old-fashioned way’. The other was the strain of not being able to access twenty-four hour home support, or the cost of twenty-four hour rest home care. After conducting the interviews, I learned that in fact twenty-four hour home care is available via district nursing, when death is imminent. However, in most cases, it seems, this is difficult to predict. The women I spoke with did not mention this, so I assume they were not aware of the service. Grande, Farquhar, Barclay & Todd (2004) found that a key concern for lay carers was being able to access the basic support that enabled them to sustain EOL care in their homes. With the current shift towards providing palliative care in patients’ homes, Docherty et al. (2008) call for more rigorous research with regard to information needs and sharing between caregivers, patients, and service providers, as opposed to the traditional patient-service provider dyad.

The stories should be read bearing in mind the following. Five of the participants responded to either a community notice or a newspaper article that provided background information about the study. A more detailed information letter then followed. When writing these, I explicitly tried to maintain a neutral stance, simply stating that I was interested to hear about people’s experiences. I avoided using words such as bad or good. However, the stated aim of improving rural EOL care in the future may have

implied that I was more interested in ‘bad’ stories, because that is what I mostly heard. Furthermore, the fact that I was a researcher, undertaking a project that had the potential to reach people with the power to make changes is likely to have influenced the way in which the women spoke with me. In this way, many of these narratives are motivated by a particular purpose, in other words they may best be understood as social performances (Murray, 2000), doing political work.

In this respect, each participant came into the interview situation with ‘an axe to grind’. For example, Neroli (all names are pseudonyms to protect participants’ anonymity) had witnessed “too many unnecessarily traumatic deaths”. Lillian wanted to talk about the need for more information and training for informal carers. Tavae responded to my newspaper article because of an incident that had happened while she was caring for an older woman in a rest home and wanted to speak out against euthanasia, whereas Jill questioned the prolonging of life through medical intervention.

Telling a story

Although I deliberately chose a conversational-style interviewing method in an attempt to replicate everyday talk and to bring a sense of equality to the interview situation, it is inevitable that the participants felt that I had more control over the process than they did. For example, I was the one who asked the questions, which initially dictated the answers given and the stories told. In this respect, the participants politely answered my questions, especially if they were on a topic that was not especially relevant to their own situation. However, given the opportunity to talk about what was close to their hearts, the tone of the interview changed noticeably, to the extent that at times the participants took charge. For example, prior to the following excerpt, Catherine had generally been

responding with one-sentence answers. At this point in the interview however, she animatedly related a story to me that had obvious significance for her. We had been discussing her husband's wishes as to where he wanted to die:

C: He wanted to be at home ((softly))

B: He wanted to be at home, but that didn't happen?

C: No ((softly)) it, it, oh he had 10 days in Hospice

B: In [city]?

C: In [city]

B: Ok, so now tell me about how that happened

C: Aaaah (..) well it was really through the (1) through the district nurse, they, they were co (.) at this stage they were, the district nurses were coming every day and (1) this particular morning (.) Hospice people had been in ((emphasised)) that's right, they came in, in the morning and they (.) they chatted away and some (.) times he was really quite lucid and sometimes he (..) wasn't and at this stage he really actually couldn't get out of bed

B: Right

C: and ah (2) they offered me (.) a place (.) at Hospice for him that day and ah (1) I ((short laugh)) said "oh no I don't think he's ready".

B: mmmm

C: "He does want to be at home"

B: mmm

C: "I really do want to keep him here"

B: mmm

C: and ((louder)) (.) then the district nurse must have come in the afternoon
((softly)) (.) that was the day from hell ((emphatic))

B: mmm

C: and (.) she said to me, she said, “you know he doesn’t know where he is he’s just absolutely away with the fairies”, she said “I can’t get him up, I can’t do anything with him”

B: mmmm, was he on morphine at that stage?

C: He had no pain

B: [No pain

C: [But he was on a very very low dose,

B: [low dose, ok

C: [low dose of morphine really to help his breathing I think as much as anything else

B: Right, yeah

C: And um, (3) she said “I’ll go back”, she said “I’ll go back and I’ll talk to the hospice people, I’ll see them later” you see and then, and then (loud) (.) the (.) laboratory people came to take blood (.) ((laugh)) and that was an absolute nightmare, because they, his veins were collapsing ((softly)) and she eventually got some blood and she came out to me and she said “Oh he’s wet the bed”, so she said “Oh, do you want me to give you a hand to change him?” and she said, “By the way I was a nurse” so, so she gave me a hand to change him. Then the Hospice people came back and they said “look he really does need to go”
((softly))

B: Right

C: So (1) he went (.)

B: [so

C: [the next morning

B: By ambulance, or

C: By ambulance (ironic tone)

B: Did you go in the am, you would have

C: I went (...) in the ambulance (emphasis, ironic tone)

B: So that left you down there with no car

C: Yes. But just a minute. [name] said to me when she organised the

ambulance “you will have to go with him otherwise they have to double crew”.

And I said “no I don’t mind going, that’s no problem at all” ((softly)). Well, when

the ambulance pulled up here there was somebody else in it (2). They said “oh

no you can’t come”. And I said “look I was told I had to come”

B: mmm, mmm

C: I had my bags packed. Soo, ((sigh, louder voice)) they took me (.) and it was

a journey from hell ((emphasised loudly)). This other woman was sick ((angry

tone)) all the way down. They had to stop every five minutes

B: There was another patient?

C: Another patient!

B: Oh ((disbelief))

C: ((laugh)) And then to cap it off I got a bill for \$500 ((laugh)). So I talked to

[name] about it and she queried it for me and she said “don’t pay it”. She said,

“in any case, if anything, you should only have to pay half of it because that’s,

you know, the full price of the ambulance”. (1) So (.) I went away to Australia to

stay with my brother (.) I guess I was away, what (3) all in all I suppose was

away for a month and when I came back home there was a thing threatening to sue me

B: Oh no

C: But however, its all sorted (.) now

I have reproduced this narrative, which lasted for just over four minutes, in its entirety, as an example of how a narrative is ‘performed’ (Riessman, 2008). The story begins in response to my question, “Ok, so now tell me about how that happened”. After a moment of reflection, the conversation becomes more animated, the pace of speaking picks up, and there is more emotion in the narrator’s voice. Structurally, it contains many of the elements of a narrative (Riessman). The story line, or plot, develops sequentially, with one event following another and the introduction of different characters. The story concludes with a resolution, “But however, it’s all sorted (.) now”. In other words, there is a plot with a beginning, a middle, and an end.

Throughout, Catherine changes tenses, presenting reconstructions of conversations in the present tense. It is unlikely that these are the ‘actual’ words spoken.

At one point, when I realised that Catherine had been left stranded in [city] without a vehicle, I tried to change tack because prior to the interview I had identified travel to specialist services as a particular challenge for rural people. However, Catherine was not to be diverted, firmly saying, “yes, but wait a minute” and carrying on with her story. Because of its intensity, this ‘felt’ like a story that needed to be told. Throughout, Catherine positions herself as not being responsible for the decision to move Graham (pseudonym) to the Hospice. She did not want him to go, because *he* would not have wanted it. So, perhaps as a way of coping with not being able to grant Graham his wish,

she removes herself from the action, describing the day as if she was an onlooker, watching a sequence of events unfold, one after the other, so that in the end the decision was inevitable, and not of her making:

C: they said “look he really does need to go” ((softly))

B: Right

C: So (1) he went (.)

The ambulance journey the next day added insult to injury, with the inconvenience of having to stop constantly (every five minutes, which is surely an exaggeration) for a sick passenger. Again, this was something that was beyond her control. In addition, Catherine shows no empathy for the sick patient, presenting this part of the journey as a nuisance that, having made the decision to go, served only to delay the transfer, making it even more distressing than it already was for her. However, the final insult was not only being charged full price for a traumatic journey that she did not want make, but also to be threatened with legal action for not paying for it. She concludes her story and resolves the action by saying, “however it’s all sorted (.) now”, which perhaps serves as a metaphor for eventually coming to terms with her guilt, which she mentions in a later conversation, for not being able to keep Graham at home.

Rural stories

Travelling

Later in the interview, Catherine was speaking about the value of friends when she remembered that I had asked about how she got her car:

B: Because (...) who, who do you think was your biggest support, was it (.) because your family wasn't here (..) was it friends?

C: It was friends

B: Friends? And neighbours

C: [Yeah

B: [Yeah? So when you were down there in [city] in those last days (..) those people are not around you

B: [to give you that support

C: [I did have my, some of my friends came down.

B: Yes

C: That's how I got my car. They, they came down and they took me back home (..) and (..) I stayed here overnight and took the car back in the morning.

B: [Right

C: [So I had, but I did have some friends down there too that were calling in.

B: Right, right

C: And they were really, really good support (.)

B: Yeah, yeah ... So if you don't have those friends around you (.)

C: Oh you're sunk,

B: Yeah

C: you're sunk

Catherine only fleetingly acknowledged that friends came down to [city], picked her up and took her home. The next day she drove back down to [city] in her own car. Overall, this meant travelling time of almost four hours and over three hundred kilometres.

Catherine could have expanded on this event, turning it into a narrative in its own right.

In fact, she chose not to. In this way, Catherine, as well as the other participants, made light of the inconvenience of living in a rural area, over 100 kilometres from specialist hospital services. The issue of having to travel long distances to access specialist services did not feature in the women's talk, except as a response to my direct questioning because it was something that I was interested in. The reasons for this could be twofold.

It seems that rural people, having consciously made the choice to remain where they have long-term memories and established social networks, accept the inconvenience of living some distance from services, finding their own solutions and ways of managing, often with the help of friends and neighbours. However, this kind of coping is often borne out of necessity (Davis, 2008) and should not be interpreted as not needing better services or support. Secondly, from the tone of the interviews, I suspect that, given the opportunity to speak about the experience of EOL care, rural issues were incidental to the overall experience. In other words, caring took place in a rural setting, which was regarded as a part of everyday life that you just got on with, whereas caring for someone who is dying is an extra-ordinary experience. Therefore, in general, unless specifically asked to talk about their experience of EOL care as rural people, all of the participants positioned (Murray, 2000) themselves primarily as carers.

Good old-fashioned neighbourliness

Like Catherine, Janet was particularly grateful for the help and support of friends and neighbours. Having recently moved to [town] she and her husband became members of a country church, with a small close-knit congregation, which is where Paul had chosen to have his ashes buried. Many times throughout the interview, Janet brought the

conversation back to the topic of the church and neighbours and the care they had shown her, in terms of practical help, information and psychological and spiritual support. Janet and her husband had immigrated to New Zealand many years ago, with Janet having come from an area where although care of dying people happened at home, women were not involved in the funeral details or proceedings. She told the following story in response to my disclosure that I had had nothing to do with dying people until the death of my father:

J: Yes that's true ((softly)) ... yes that's exactly it and I had not had any contact with death of a relative either and as I said that's where [name] was just so helpful to me

B: mmm, mmm

J: um, because my family all died over in [country]

B: So tell me what it's like over there when someone dies

J: well it's changed now of course, but in my day (.) um I remember when my father died (.) way back (..) I was eight at the time (.) it was a long, long time ago. The funeral service was held downstairs and Mum and me and our sisters, you know female members, were up there, they don't take part in the service

B: mmm

J: And then (..) they were, there was no supper or (.) teas or anything like that, just the men just carried out the coffin, put it in the hearse and it was (..) at that time it was drawn by horse ((emphasised as the thought occurs))

B: mmm

J: and everybody that you passed would stand to attention and bow their head

B: Really,

J: [My father

B: [very formal

J: Pardon?

B: Very formal

J: Very formal

B: mmm

J: And then up in the country areas what they used to do is take a bottle of whisky with them, and they walked all the way to the cemetery (.) and had a snifter of whisky every (.) my husband went with my brothers (.) to somebody's funeral up in the [area of the country] ((laugh)) he was absolutely aghast ((laugh)) because he was from [a different country] you see

B: mmm

J: ☺ And um of course they were all half sizzled by the time they got to ((laugh))

B: By the time they got there. So would they, back in those days, would they have cared for someone who is dying at home?

J: Yes, absolutely, absolutely

B: Yes, yeah

J: And ah (.) yes, definitely cared for at home (.) there's no doubt about that at all ((softly))

Thus, the only model Janet had, for how and where dying should proceed, was a distant childhood memory of the way things were done in her homeland over sixty years ago. It is possible that this influenced her decision to take Paul (pseudonym) home from the hospital. It is also possible that Janet's experience of country life is coloured by her

childhood experiences, growing up in a close-knit rural community with a traditional way of life and traditional values. The following is a composite narrative of the several occasions when Janet spoke about how her neighbours had helped her with planning and catering for the funeral as well as taking care of maintenance chores that Paul would normally have done:

J: My um (.) I've got the most wonderful neighbours in the world and across there is [name] and [name]

B: Oh yes

J: and [name] has been absolu (.) just like I call him my big brother. He came over and told us what the procedure was and (..) umm suggested told me all about the funeral directors and what they do and so on. The minister came in and sort of gave the last rites to Paul and um (.) he just filled me in on everything. So [name] was wonderful, [name] was great too, just wonderful people,

B: [mmm

J: [people across the road there, um [name] and [name], absolutely wonderful people

B: Had you got to know them before Paul became ill?

J: ...they just made friends from the time we came

B: mmm

J: and I was listening to a minister at the weekend (.) and he was saying that (.) how you can (.) you know love for your neighbour and all that

B: Yes

J: I'd say that I have had love given me more than I ever, ever expected and people thought when I, Paul died, that I would move to [city]

B: mmm

J: No!

B: No?

J: I'm happy here,

B: Yeah

J: I'm very happy here. I have all the support I need. I have a neighbour over there who comes and does all the bits of jobs, men's jobs.

B: mmm

J: He put up the end of my fence for me (.) he's fixed a door (.) he's gonna paint that new door that I've got and they're just wonderful. His wife and I are going down to pick rhododendrons tomorrow to put in the garden, and I'm just surrounded by beautiful people...

J: And I have a lovely church. I go out to [name]

B: Oh yes

J: ...and oh [name] there came over every day, every day

B: Every day

J: [name] across the road came across and

B: [So your

J: [People brought me

B: [neighbours and your friends really

J: And the church.

B: [and the church

J: [The church people organised the um (.) afternoon tea, you know the meal after the funeral

B: mmm

J: [name] and [name] organised the hall just across from the, you know the Presbyterian hall, I really (.) just didn't have to do anything,

B: mmm

J: they just did everything for me

B: They did it for you, mmm

J: And I shall never forget them and I shall live here for as long as I possibly can

B: [can, because of that?

J: [pardon?

B: Because of that do you think?

J: Yes because of that. I have everything I could possibly want

The excerpt above, narrated with a great deal of warmth and conviction, fits the stereotypical portrayal of country living, where people enjoy living in caring, supportive communities. It seems if she did not have the support of her neighbours and the church Janet would be very lonely. Because of this, she is refusing to move to [city] to be closer to family even though they have asked her to do so and others thought she would:

J: people thought when I, Paul died, that I would move to [city]

B: mmm

J: No!

B: No?

Much later in the interview, Janet talks about how her children were “terribly devoted to their Dad”, wanting to do everything they could for their father, offering to pay for unsubsidised drugs in the hope of a cure, re-arranging Janet’s home to make things nice for their Dad and taking turns to care for him. Then, she reveals that since the death of their father, her children no longer visit her and she cannot understand why. Now that Dad is gone, they have left their mother to cope, on her own. Thus, on one level Janet paints an idyllic picture of living in a supportive community where she is well cared for by her neighbours. This is the story that she wants me to hear, saying things like:

“...I’m very happy here. I have all the support I need...they just did everything for me... I have everything I could possibly want and I have had love given me more than I ever, ever expected”

On the other hand, at the same time, she is justifying to herself why she should not move. A strong woman, who has always been in charge of her life and her career, it seems she will not be persuaded to move to make things easier for her children. With the love and care she has here, why should she move to be near her family who have not been to visit since Paul died:

J: they always used to be coming down, running down to [town] for the weekend and taking the little girls (..) Dad's dead

B: Yeah

J: Gone ((louder)) I'm here

Mobility and diversity

Janet's portrayal of neighbourliness is certainly more positive than Lillian's perception of rural life, as she laments the changes in rural living that she has witnessed during her seventy-plus years of life:

B: Do you think it works quite well that people know their neighbours, and so there is that support? Do you think that would be a positive thing about living in [town]?

L: I'm actually shocked at the fact that (.) for example (.) if I look back on my childhood, to even today I can start at the bottom of the hill and tell you the neighbours all around the whole street. On both sides. Today we have, because a lot of people work, a lot of people are so busy doing other things (..) they basically get in their car they, they drive out of the street (.) and they come in again and walk back into their house. And so I would (..) rashly say (..) that if you asked the majority of the people today they would be lucky if they know (..) three to five people in their whole street

B: mmm

L: And (..) that is (.) an indictment on the world today.

In addition, Neroli, Tavae and Diane, who are involved with rest home care, have all cared for rural people who have few family and friends coming to visit. The trend towards smaller families, the movement of children away to larger towns and overseas for employment, and retirement to cheaper rural areas means that, in general, older people no longer enjoy the traditional extended family networks that once were characteristic of rural, or pastoral, living (Kellehear, 2007). Neroli, Tavae and Diane's

stories highlight the diversity of rural experience and the problematic assumption that rural people enjoy more social support than their urban counterparts do. In addition, Tavae's story shows that even those with family who come to visit sometimes find the contact stressful rather than supportive.

Neroli is an enrolled nurse, with thirty-five years experience, who was clearly the most politically motivated of all the participants, speaking eloquently and forcefully about many issues, often pointing out deficiencies in the 'system':

N: And (.) there's this huge myth out there that all these people have got a family because a lot of them don't (..) So you've got people in rest homes, two nurses on doing their best, having to cope with 35-40 patients and literally (.) you go in to see if they're dead yet (..) and that's about all you have time to do ... I mean this chap (..) umm (..) he used to live in a caravan in the [town] camping ground for years and years and years. I think he's got very few family members anywhere, umm ... and probably, when he was admitted, to be fair, umm, he wasn't requiring, he was basically independent, but it was known that he had a rapidly progressing disease (..) And rather than relocate him to [hospital] now, because he's needing more care, they hang onto them. Which, and, quite often this is what the patient wants too, because it is familiar. And also, I suppose they think if they make the decision that they now need somewhere else they are actually admitting to themselves that they're (..) dying.

B: mmm, mmm. Yes because you said before, didn't you, that he considers the rest home to be his home

N: His home (.) in fact he's had you know he thinks he's (.) originally when he arrived there I mean clean sheets, clean room (.) someone cooking all his meals for him. You know, its like landing on his feet

Diane is a rest home owner. Her response to my question about people having family or friends coming to visit also shows that it cannot be taken for granted that all rural people enjoy the company and care of extended family:

D: Um (.) I mean that comes and goes. You (.) I mean (.) we do have people who (.) yeah (.) essentially don't have family, and some who don't have family that bother with them. You know, they do have family but because of some family dynamics in the past

B: Yeah

D: Um (..) but I mean I can think of three instances off the top of my head (.) um one lady who's just got two (.) like married, husband's died, no children of her own, she's got two nieces, they live in Australia, so she has no local contact. ... another lady (.) another man I mean (.) who um, his wife has died (.) um he has come from England originally, got a daughter and son in England, but no family here in New Zealand... um another man who's got a son here in [city], a son in Australia, but marriage split up and he's become estranged

Tavae has been a rest home care assistant for nearly twenty years. She cared for her own mother before she died and stated several times that she cared for the rest home residents as if they were her own family. In the following story, she expresses her concern for the residents whose family did not come to visit, or when they did come

showed no respect for their elders, which having been raised in a culture that has a deep sense of love, respect and family responsibility (Schwass, 2005), is difficult for her to comprehend:

T: ...its quite a lot of people I'd be there for them

B: mmm?

T: When they die alone

B: Do you think many people don't have family when (.) when they come into the rest home? [Many people that don't

T: [Yeah

B: have family visiting?

T: there's a lot

B: A lot?

T: Mmm.

((muffled talk together))

Some come from the church, they visit. They come, yeah they come like that and visit. But they hardly (1) maybe live far away. So I notice, I think if a resident (.) has a lot of aah family (.) children coming to that resident, so I talk to, I said to that resident, "you must be good to your children when they young" and they say "yes".

B: Yes

T: And the, and the children say "oh yes he's a good () he's a good father or a very good mother". So I notice if you are good to your children ((laughs)) they return the favour ((laughs)). And it is something like that. I notice too. And another thing I notice (2) for people who, you know those children never come

and visit? But when someone, when they pass away they all came in looking for things.

B: Ah

T: Asking for clothes or watch or something like that. But where were they (.) when the person needed (them)?

B: You find that sad?

T: I find it sad to (.) to notice that thing... and some other thing that people, children come and argue in front of their parent (..) what I notice

B: mmm

T: They argue about the estate or something. One might using, one, the other one might be using more

B: mmm

T: There was a lady there was very old, and I said very (.) "I think is want to go" but I said to one of the girl, "I think your Mum want to go but you people have to sort out" ((laughs))

B: What did she say to that?

T: And she said (.) and she said (.) and she said, "I can't talk to my brother". But I, to me in my own way, in my own thinking, the lady wants to go (1) but because of the fighting all over the (.) () I said "I think you sort out you, you and your brother (.) your Mum wants to go, but its you two" ((laughs))

B: mmm

T: I just aah and she said, "I have to go to, to talk to my brother"

B: Yeah

T: And then another few (.) she's gone ((the mother had died))

These stories provide varied examples of rural life, as well as how different backgrounds and experience inform each point of view, highlighting the role that social context has to play in how we construct and understand the world in which we live. This is an observation that surfaces repeatedly throughout the chapter.

Getting services right and accepting help

Despite the perception that help is readily available in a rural community, Catherine and Janet, who had spoken about receiving help from friends and neighbours, both said that they did not like asking for help, and at times would not accept offers of help, preferring to cope on their own:

B: So did you have contact with the Cancer Society?

J: Ye (2) A little bit

B: A little bit?

J: Not very much though

B: Because it was

J: They came and visited, they invited Paul down to a (.) a group meeting that they were having and he wasn't able to go

B: No

J: Um, (2) I can't remember her name (..) she said keep in touch, but I never did

B: mmm

J: [Um the ...

B: [Why was that

J: Well I didn't really feel there was anything they could do for me

B: Ok

J: Aah the best they could offer would probably be somebody who'd look after Paul for an hour

B: So you could pop out and do some shopping

J: And I don't think Paul would have liked that

B: Aah

J: He'd have been upset by that

B: Yeah

J: [name] across the road used to offer and say "Janet it's time you had a (.) had, went out" but I never did

B: mmmm

J: I just stayed, this is my place I will be here until he dies

B: Right

J: And that's what I did

B: That must have been hard for you though, not being able to get out (..) do you think?

J: Yeah (..) in some ways, it didn't bother me that much really. I've got my little dog that I walk and that was really all I wanted... I had to feel that I had done my very best. I had to feel no guilt after Paul passed away. And that's what I feel, no guilt, because I did my very best, right up to the end

While Catherine too wanted to keep her husband at home because that was where he wanted to die, she would not ask for help either, unless it was from family or close friends:

B: So if you were to give any advice or recommendations for people caring for someone, is there anything you can think of that would have made your life easier, or

C: (5) No not (.) not really (2) umm because there's (...) really help there, if you need help. See the Cancer Society will provide somebody to (.) come and sit if you want to go and do your (.) shopping. But, I'm not one that likes asking for help

B: You don't like asking

C: No. I'd rather sort of plod on ((laugh)). But my friends would, they, [name] the guy that came in, he often came and sat with Graham while I went down and did the shopping

B: Right

C: which you know, makes such a difference cause being tied to the house is so difficult (...) 24 hours a day really

B: mmm, and wondering if the buzzer is going to go...

C: Yeah ((laugh)) yes

B: So (1) friends are, are a huge support

C: Friends (1) friends and family

Both Janet and Catherine refused outside agency help but for quite different reasons.

Initially, Janet states that it was because Paul could not go to the meeting and then that he would not like her to be away from him, however she concludes by saying that she had to feel no guilt, and that she had done her very best for Paul. This need to be in control of Paul's care is something that surfaced several times throughout the interview.

For Catherine it was simply a case of not wanting to ask for help. Again, this 'stoicism'

recurs several times throughout the interview, helping me to build a picture of the kind of people Catherine and Graham were and influencing my interpretation of Catherine's stories. For example, when Catherine expressed disappointment that their GP did not just come and visit, she had to ring him if she needed him, she pointed out that they were not the kind of people who would bother their doctor needlessly:

C: And we haven't been people that have (...) gone to a GP at the drop of a hat.

B: Right

C: You know, we're not panicky people, you know, you go (.) because you've got something specific wrong with you. I know some people (.) you know, live on doctor's doorsteps but no (..) you know and I just thought well you know he could have ((come to visit))

And later on when I asked her if she had used any spiritual or psychological support services she said:

C: I don't think I was ready to

B: You weren't ready to?

C: No, I don't think so

B: No. And what about afterwards? Did the hospice have a bereavement

C: Yes (.) I've had, I've had something from them (.) recently (...) that I can go if I want, [but I don't, I've worked through it

B: [But you've worked through (.) on your own

C: Yeah, yeah,

B: Yeah

C: I think so

I chose these examples to emphasise the complexity of providing EOL care. On the one hand, the results could indicate that rural people simply do not want the help of outside services. On the other hand, however, I think this is a superficial answer. If there was better co-ordination of the services and providers had the time to get to know their 'clients' better, assistance could be tailored in a way that is more appropriate for individual situations, which is discussed further in the next section.

The burden of caring

The reluctance to accept help from service agencies like the Cancer Society can be in spite of experiencing extreme fatigue, physically and mentally, as Janet points out:

J: There is just one area that I would say (..) umm could be improved upon (.) for someone in a different situation from me. I had family (..) I had friends (...) people all the way around here, so I didn't have to think too much about it

B: mmm

J: But if there was somebody (...) in an area where they didn't have the support of family (.) and they didn't have very many people around (..) the problem is night care

B: Yes

J: Now, the one night I cared for Paul on my own (..) it was very, very hard

B: Yes

J: Because I kept wakening (...) what's he doing (...) hop across, see what he's doing (..) 2 o'clock in the morning (1) he's pulled out his catheter (.) he's trying to get out over the cot sides (2) and you know it was just so hard.

B: mmm

J: The bed's all wet (..) I'm by myself (..) and I just said to Paul, "you should not have pulled out this catheter, now you're goin' to have to help me coz I can't do this on my own. I've got a back problem"

B: mmm

J: "Now we are gonna have to go over to that side" and I put in two draw sheets,

B: mmm

J: two disposable draw sheets so that kept him dry

B: mmm

J: but waited 'til the nurses came in the morning

B: [mmm

J: [(), you know I couldn't do it by myself

B: And you have (.) a nursing background as well

J: Yes, I'm a registered nurse

B: mmm

J: [] trained

B: mmm

J: And ah (2) having worked with old people and

B: so for somebody who had no background like that it would have been even

J: An absolute horror

B: mmm

J: And to (...) lack of sleep (...) would be a killer

B: Lack of sleep, mmm

J: Now (..) I know that you get a certain amount of (...) back-up for evening care

B: mmm

J: but really, it's not enough

Lillian, an informal carer for more than thirty years, also had a story to tell about the burden placed on family carers and how the respite care 'system' had failed a lady that she was caring for:

L: Now I had a situation which (.) I'm still angry today over as far as that's concerned. I was caring for (.) a person (.) um, only just one day a week (...) and then (...) and she had to go into hospital because she herself was sick but her husband had to have caring (.) but he was only having caring certain times (.) but when she was in hospital he had to go into respite care because he wasn't able to be by himself because he was quite a bit older than she was. And (...) so she would be in hospital but because of today's situation (.) they would put her out of hospital say after the fourth or fifth day (...) and send her home. She would be allowed the next three or four days to recoup before her husband was sent back from the rest home, back to home where she had to not only re (.) recoup her own health but deal with his ageing health problems and after just a matter of weeks (..) she got so ill again that she needed to go back to hospital. He was sent back to respite care (...) and (...) the same thing happened. Within

a matter of 24 or 48 hours he would be sent back from the respite care because she was already home

B: Oh dear, oh dear.

L: even though she was still picking up her own health.

B: Oh dear

L: So (.) um (...) so that happened three times and on the third time she asked them and begged them and even through the doctor asked for them to keep him for another week (...) and they declined coz she had just about used up all her respite care. The fact she had used it up because she'd had to go to hospital didn't seem to come into the agenda at all (...)

B: Oh dear

L: and they said "well you've used up your respite care" and she said "but I've had to go to hospital (...) the three previous trips " so they still sent the husband home and approximately three days after she came home the last time she took sick and died (...)

B: Oh dear (...) Oh dear

L: ...and that is just (.) I'm so angry at that.

B: So what age would she have been?

L: She would have been in her mid-80's.

B: [Oh no!

L: [And he would have been in his mid-90's.

B: And they were expecting her to care (.)

L: Yep.

B: Oh dear.

L: And I think that respite care should be just that. Resting (..) time. The fact that she'd used up a lot of it because she'd been in hospital should have been granted as an extra...and I was so, so angry...I was just so emotionally upset by one, of her dying alone, um but also knowing that it had been caused by the respite care not being picked up properly.

Catherine too, spoke about how not having access to twenty-four hour back-up places a burden on informal or family carers looking after people in their own homes:

C: I got terribly tired.

B: Yeah

C: And I (..) you know I wasn't sleeping because he had a little buzzer thing and if he wanted me he buzzed me...there's not (..) there is not an awful lot that you can do because the government (..) or the state (..) or the hospitals can't provide 24 hour care at home

Lillian and Catherine's stories especially, describe needs not being met. The service providers in Lillian's story appear to have failed the woman who, (in Lillian's view) died because of their inability to respond to her specific needs as a person, rather than as an objectified recipient of allocated services. Solutions to such problems can usually be found, but in this case, it seems, a humane or even commonsense approach was totally lacking.

In another conversation Catherine makes the point that despite the best of intentions, things change:

C: And I mean (.) you know (.) I'd said to him that ok (..) I'd look after him and you know (.) he could die at home but in reality it's just not possible sometimes

B: mmm and you know the studies that have been done, that's where people do want to die

C: mmm

B: [is at home

C: [it's at home in their own bed, but he couldn't even have his own bed

B: So did you feel (.) did you feel a little bit let down because your wishes or do you think (...)

C: [No, not really let down,

B: [you didn't (...)

C: I think everybody did what, what was possible

B: Yep (...)

C: But short of employing somebody for 24 hours a day

B: mmm

C: It just isn't possible to be at home. I mean I couldn't have given him the care that hospice did.

B: No

C: Particularly when he was unconscious,

B: mmm

C: you know (..) and he had to be turned every 2 or 3 hours (...) Impossible

B: You couldn't have done that

C: No

B: So do you think sometimes when we (..) when we say that this is what we'd like we actually don't (..) we don't know what it's going to be like and it changes

C: It changes (1) it does change. His idea of it didn't change (..) he still wanted to be at home (..) he didn't want to go to Hospice,

B: mmm

C: there's no doubt about that (.) but ah (..) in the final analysis it really didn't make any difference

B: mmm

C: because he didn't know where he was

B: Right, right (...) but its (.) its how you felt (.) that that last little bit

C: I felt I let him down ((softly))

B: Did you?

C: Yes, I did (..) I did do my best

B: Of course you did,

C: Yeah

B: of course you did

C: But

B: and it's a shame that

C: There's always (..) you know (..) you want to grant them their wishes

B: Yeah, yeah

C: but realistically it's not always possible

The preceding conversations provide some insight as to why caregiving is considered one of the most stressful social situations (Dulmus & Rapp-Paglicci, 2005). People caring for relatives at home may feel the need to be available around the clock, especially partners who take on a larger share of the caregiving burden compared to other caregivers (Rees, O'Boyle & MacDonagh, 2001). Or, like Janet, they may want to

have control of the caring process. However, the physical demands of providing that care, are often more than they can cope with. This is understandable, given that most of these people have no formal nursing training, yet the level of care that they are expected to provide, and they themselves want provided, can be as technically complex as that which would be given by trained nurses in a hospital setting. In addition, many carers are women over the age of 65, with physical problems of their own, such as bad backs and arthritis.

Unless they self-identify as informal carers and enrol in courses that provide information about caring, including safe lifting techniques, these people risk jeopardising their own health. Catherine had no formal training, picking things up in an ad hoc manner, and making do as she went along. Bee, Barnes and Luker's (2008) review of the research on informal caregivers' needs when caring for cancer patients at home found that there is a lack of practical support, which is often due to a lack of information sharing. This typically results in relatives adopting the 'trial and error' approach to palliative care to which Catherine refers.

Janet had trained as a registered nurse in a previous career, yet she too struggled with the demands placed upon her over the three weeks that she cared for Paul at home. It appears that specialised care has been transferred to home with the expectation that untrained, family providers can take over. This is usually in deference to the wishes of the person who is dying, or of the people who are caring. However, it is probable that no-one really knows what is in store, especially with regard to the length and extent of care required. In addition, a similarity appears to exist between the perception that dying at home is a natural and necessary component of the ideal or good death, and natural

home births, which were something to aspire to in the 1980s. Moreover, I recall an implicit sense of superiority if you could deliver your baby without needing pain relief. The satisfaction from achieving this ideal however, was offset by feelings of inadequacy and failure when this did not happen. It seems there is a danger of this happening with home deaths, when the person who is dying does not remain at home until the end, as in the case of Catherine and Graham. In this respect, the psychological ramifications of not being able to cope with EOL care, “I felt I let him down” may be as important as the physical burden of caregiving.

The women appear to contradict themselves when they say that one of the problems of rural EOL care is the lack of 24-hour support, and yet they refuse the help of agencies such as the Cancer Society. Another way of looking at this is that we have yet to get the services right for people who are dying, and their carers (Dy & Lynn, 2007). In this instance, overnight support would have been appreciated.

Catherine’s story of Graham not being able to die at home comes as no surprise. A common reason why patients are admitted to institutions is to relieve family of caregiving responsibilities (Rees, O’Boyle & MacDonagh, 2001). Furthermore, even though most people would prefer to be cared for and die at home (Higginson & Sen-Gupta, 2000), the majority of people in developed countries die in hospital (Gomes & Higginson, 2008). The trend in countries such as the US, Australia and Canada is towards more people dying at home, however the number of home deaths in England is decreasing (Gomes & Higginson, 2008). In New Zealand, the number of people in residential care is likely to increase by 83% between 2001 and 2021, despite the ageing in place initiative to support people to stay in their own homes for longer (Cox, Hope &

Davies, 2004). If this trend continues, and it seems likely that it will, then it becomes even more important to address rest home and community (rural) hospital care for people who are dying and their carers.

To treat or not to treat: Part One

For example, one of the criticisms that Catherine made of rural hospital care was that it was not appropriate for people who are dying, the biggest issue being too much intervention:

C: I knew he'd had enough and he just wanted to be (.) left to die

B: Yeah, yeah

C: But we kept getting these interventions ((laugh)) I just feel that this is what's lacking (.) lacking in a small town is, is your (2) specialist care in that side of things. They're fine (1) at [hospital] for healing (1) but (3) I think if I had said to them no I don't want any intervention they'd have said ok take him home. That was the impression I got

B: mmm

C: I could be wrong

B: So what you're saying is if you had said that down there they wouldn't have allowed him to stay in the hospital

C: I don't think so

B: [without any intervention

C: [No, no

B: So therefore your next choice was Hospice

C: Yes. So you see he got a chest infection when he was there so they treated his chest infection. Yet he got a chest infection at hospice and no, they don't

B: Oh, interesting

C: They let things run their course (.)

B: [course

C: yeah. He wasn't (.) it wasn't distressing him,

B: ... and did you (..) say at any stage to the GP we don't want to go to the hospital, we don't want any intervention

C: I think that, think that by the time, when he went into hospital he really did need to be there because he was getting beyond (..) me

B: Right

C: and they'd stabilise him

B: Right

C: get, get his (2) calcium level down and his (2) haemoglobin level up and he'd come home

B: Come home

C: And then his body would just start (3)

B: Back down onto

C: Back onto the downward slope again

B: Right, right, yeah. So, your choices were basically at home (1) until you couldn't manage anymore and then you'd go to

C: He'd go to hospital (...) I felt that (2) the hospital here weren't really equipped (4) to let people die (...) that they were equipped (...) to keep people alive
(softly)

B: More equipped to keep them alive. So, yeah

C: Yeah

B: Yeah. I know exactly what you are saying

C: Yeah, you know he'd go in there and they'd fill him with blood and send him home.

B: Yeah

C: Another 3 weeks, back, more blood

B: Yeah, so they could do all those um

C: They did all those things which, which really was intervention and this was the difference at Hospice (2) there wasn't any intervention

These comments from Catherine demonstrate the paradoxical situation that she faced as a carer. On the one hand, she felt that the hospital intervened too much, for example, when they treated Graham's chest infection. On the other hand, Graham needed to go into hospital for regular blood transfusions because without them Catherine could not manage him at home. By the time that Graham was transferred to the Hospice, Catherine felt she was no longer able to give him the kind of specialist care she thought he should have, and yet she did not want him to have the kind of care that the local hospital could provide. In addition, as indicated earlier, Catherine felt she had let Graham down because she was unable to provide the kind of care she wanted him to have, at home where he wanted to die. What would have worked best for Catherine would have been for Graham to stay at the hospital, close to his own home, but with the kind of care that Hospice provided.

When Catherine states that "he couldn't even have his own bed", she implies that Graham's wishes are secondary to needs of the nursing staff who would find caring for

him in an ordinary bed too difficult, hence the need for an electric bed, which can be raised or lowered for safe lifting and turning. However, the most interesting aspect of Catherine's story is that she feels that she lacks the skills to care for Graham, "I mean I couldn't have given him the care that hospice did". This implies she believes that caring for dying people is not something that family can do. It is a specialised job that, for the sake of the patient, is best left to the experts. How then, can lay carers be expected to cope with taking back the role of caring, at home, if the dying process has become so complex and technologically advanced?

Caring stories

Changing needs in rest homes

This is also an issue for rest home care. Diane spoke about how rest homes have changed just in the last five years since she became a manager and then owner of the home. Five years ago, the majority of residents were long-term occupants, some of whom had already been there ten or eleven years, living out their final years in pleasant surroundings with someone to care for them. Now however, hospitals often transfer patients with complex, co-morbid illnesses with unpredictable trajectories, for shorter, more dependent inpatient stays (Currow and Hegarty, 2006):

D: I mean the criteria now for um (..) because there's a shortage of hospital beds (.) there's a lot of people come out to rest homes that you know 3 years ago would have been considered to be hospital level care. They, they will send terminal people to rest homes

B: Right

D: And don't consider that they are hospital level care, um because they may well (..) um be going to die, but they don't necessarily have (..) illnesses that (..) need 24 hour (..) registered nursing care

B: So how do you feel about that? Does that bother you, having people coming here

D: Um, I mean it's quite, it is (..) its most probably above what we're funded for. We're not funded for, because a lot of these people can be very high level care people

B: Yeah

D: Um, and there needs to be a lot of extra staff input and a lot of extra resources, like um (..) you know a lot of medication, a lot of additional medication, a lot of additional doctors visits because they're at the end stage of their life (..) ... well, I mean (1) essentially because what happens in [town] particularly, is that (2) you know (..) because there's so many sicker people, you know like the type of person that five years would have got into a rest home no longer meets the criteria, [so they're not in the system,

B: [So they're still at home

D: so the people we get are another step up, the hospital ones are another step up, so um, because you've got so many hospital people because they, you know, there's more at that end now

Diane then told the story of a woman, who was a double amputee and had been waiting in hospital for four weeks for a transfer to a rest home with hospital accreditation, but there were no spare beds. This, according to Diane, is a common occurrence, and with the number of people in residential care likely to increase, as previously mentioned, the

pressure on rest home beds will inevitably worsen. Eventually the patient improved enough to transfer to Diane's rest home. According to Diane, the hospital was, "very happy, very, very happy to get rid of her" because she was using up their resources. However, she still required medical attention over and above the rest home funding allocation. In another conversation, Diane spoke about having to call in doctors and RNs after hours to provide specialised medical care for a person, who had been transferred from the Hospice, which again was over and above what the home is funded for. This resident had a wound that was never going to heal, but they had to:

D: manage it for her comfort (..) as much as we could. So, I mean just (..) maintaining her, with that kind of wound, maintaining her with a morphine driver, that has to be administered by a registered nurse

B: Yeah

D: and we don't have a registered nurse working on the weekends

B: Ok

D: So, so over the Christmas period when we had to um get a nurse from the hospital on the stat days and on the um holiday, at the weekend days, um we had to pay for that service. We had to pay \$50 to them, to the nursing staff at the hospital. So you know if you think about the fact that you're only getting (1) well at that time I think we were getting just \$100 a day for her

B: Yeah

D: And on the days when we needed someone to come in

B: Yeah

D: that was \$50 just to have them come in and that, so that leaves \$50 for that person's feeding (..) and care (..) and wound needs (..) etc, medications, you

know we have to pay for all of that, so yeah, um I guess sometimes we're (2)
um, morally feeling we should do this for people

Diane's last statement highlights the conflict that she feels as a business woman trying to run a profitable business, while at the same time presenting herself as a good person who accepts her moral duty to provide comfort for another human being in her care. I suspect that this was not part of a narrative performance trying to convince me that she has the best interests of the residents at heart, but rather that this particular rest home does have a caring ethic (Branch, 2000; Lloyd, 2004). Later in the interview, Diane told me the story of a man who had been sent from hospital to the rest home to die.

To treat or not to treat: Part Two

The following excerpt is a composite of the conversation, which lasted for almost nine minutes:

D: I'll just get the notes to see how long he actually lived, because it was interesting, um when he actually did pass away that we were amazed at how long we actually had him, you know considering that um, I was looking at his stuff after he passed away and it had um that he was only allowed um (1) ice chips

B: Right

D: To suck on ice chips, that's what they'd discharged him saying

B: Right

D: And quite clearly if that was all he was going to have, he wasn't going to live for very long at all

B: No, no

D: He was already (..) he was already (.) I don't know, about six stone or six and a half stone then... he lived from the 11th of July to the 25th of October. Um in that time, I don't know if I've got a note of it (1) in that time he um (2) he actually fell over, he was a man with um a very severe cancer of the oesophagus, and um he had, clearly had secondaries in other places, but that hadn't been established, you know ...one dinner time, about (...) six weeks before he passed away, he fell over and fractured the neck of his femur

B: Right

D: He was with a carer, going to the toilet and he just sort of had this little black out

B: Yup

D: And she supported him to the ground

B: Yeah

D: She was there with him, but because he was so frail, he actually fractured the neck of the femur, so um, the doctor came and said "well look he is a terminal man, but we've got to do something, we just can't leave him in agony". So (.) he transferred him to hospital and he said um (..), "there's a very good chance that this will be" you know, "the end for him"

B: Yeah

D: Well he went on about a Thursday, they operated on the Saturday and on the Sunday he was up walking (.) and they said all he wants to do is come back. He's not dying down there, he wants to come back here, if he's dying anywhere, he's dying here

B: So this was his home

D: Yep, and in that short time he, you know he considered that it was his home

B: Yep

D: Um, he um, he got back here and he was fine. He was fine. ...in the last sort of, yeah week of his life you could see he was starting to slip down, but he was so (..) stoic and tough you didn't really know how close the end was (..) he'd been diagnosed and, and told you know like this is the end you're not gonna live, we can't feed you, we can't do anything, um yeah (..) so, quite amazing, yeah, mmm

B: So quality of life?

D: Oh he was good

B: Yeah

D: Yeah it was good, yeah it was good. So no there was no (..) um (...) you know there was no problem um (...) in any communication, um he maintained a normal existence almost til the end and you know he'd come up to the dining room, he'd walk up, um if he wasn't feeling so well we'd wheelchair him up, but no he was able to carry on quite normal

B: So what do you put that down to, do you think it was because you had the time to

D: Well I mean they said, they said nil by mouth because he had a gastroscopy ... and they actually ruptured his oesophagus with the instrument that they were looking with, because it was so damaged, they actually ruptured it so they didn't look any further, they couldn't, so they just took the instrument out. So essentially (..) um solid food was not an option for him...but having said that, um, obviously he still had the desire to have something

B: mmm

D: and um, we felt well if we give you a really soft diet, like a liquid diet, um, the worst thing that can happen is you might choke

B: [mmm

D: [and die, well, we felt that it was better that he died with a short life and some quality

B: [mmm

D: [than starving him to death

B: mmm

D: So you know we, we just started giving him soft food and he managed scrambled eggs, he managed fish in white sauce, he liked mashed potato with gravy on it, that sort of thing and he'd tell us what he wanted, what he felt like that day, you know and he, he ate a lot of um, chocolate and lollies and stuff like that coz he'd just suck on them, yeah, yeah and um, ice creams and you know, stuff like that, we'd just buy special stuff for him. Give him jellies, soft jelly, so he actually, I can't remember off the top of my head, but in the first um about 4 weeks that we had him he put on about 4 kilos in weight. So he actually responded to that nourishment

B: Yeah

D: And then um, yeah, then he had the fracture and then his, his general health, he had, like he had another three weeks when he, three or four weeks when he came back here after the fracture, where he was really good,

B: Mmm

D: And then the cancer started to take over again, so yeah

B: So you pretty much just treated him like you would a family member

D: Exactly, exactly

This story illustrates that it is possible for people with an unfavourable prognosis to maintain some quality of life for some time without any medical intervention, just 'good old-fashioned' comfort care. Diane then went on to say that although they know they cannot prevent the decline in people's health status, they look after each individual as best they can, by giving emotional support, reassurance and comfort.

Treatment: 9 to 5, weekdays

Neroli, the enrolled nurse, however, paints a less rosy view of (the same) rest home care. She too, talks about the difficulties associated with accessing 24-hour care, echoing Newton's (2007) experience of hospital care in Britain. In the rest home where Neroli works, the RN only works between the hours of nine to five, although there is an RN on call after hours. However, from Neroli's perspective, management are reluctant to call her in after hours because of the cost. Although she wants to work fewer hours, Neroli is constantly being called back on shift because there is no one else, apart from the RN, who has her expertise, particularly with regard to pain control, which is a key component of palliative care:

N: Even if you call a doctor in (.) the caregivers, if the patient requires say an injection, pain relief, or a morphine pump, or something like that the caregivers can't (..) do that. They haven't got the expertise (..) Soo (1) for instance the rest home that I have been working at we've got a chap there that's got CA ((cancer of the oesophagus)). He's been charted an () shot of a drug that will (1) basically if he ruptures his oesophagus its going to be a very unpleasant death. He's been charted a drug to basically (2) put him into an altered (1) frame of mind. But, there's no-one there to give it. Or, if you get the RN to come in and

give it, you've got to have the expertise of the staff there to recognise that that's what this person needs. That's what is happening. Which they don't necessarily have

B: So what happens, what

N: (2) ((sigh)) Worst case scenario he will, he will just die and they will find him. Ummm hopefully if he needs that drug they will get hold of the RN and get her in to do that

B: How will they know that he (.) they won't

N: Not necessarily (...) Or, they will know because, lets say he haemorrhages all over the place, they'll know (..) But he'd need that shot straight away. You know, not in twenty minutes time when they've managed to get hold of the RN, she's come in from wherever it is she lives (..) and given the injection (...) mmm, I think it comes down to that you need the expertise and you're not getting that. The caregivers are wonderful, but they haven't got the years of experience. They don't know how to monitor someone's pain levels

B: So that must make them feel bad, that they can't deliver the care that they know they would like to. It puts them in an awkward position (.)

N: It puts them in a terrible position. Which is probably why you get such a high staff turnover in these places ☺ ... I've resigned 3 times, its just they keep on, they're desperate, desperate. I mean I'm the only person, for a while not anymore, for a while I was the only person that could do pills...a lot of these girls ummm, either don't have the self confidence, I mean they can be trained to do the medications, its not difficult ummm, well it is quite complex, everything arrives in blister packs but then there's all the extras. And then there's also assessing people's pain and there's checking out narcotics and a lot of the girls

just do not want that responsibility. You can understand that, they haven't been trained. And even if you train them up, I mean its not, its actually quite a complex thing with the elderly, because you are watching out for so many different things. So, they don't want that responsibility. So its difficult because there's no one around to do it anymore...but again, you know you've got to have that very careful monitoring, but I think a lot of nurses just get scared and they just dope them up

This is just a small part of several very long discussions where Neroli spoke about pain relief. She repeatedly makes the point that care assistants do not have the expertise or the experience, nor do they want the responsibility of administering pain relief. She also suggests that even some of the more experienced nurses are afraid of pain getting out of control. In this way, she draws on the biomedical model of pain, which predominantly considers pain in terms of physical symptoms. Her discussion about keeping pain under control echoes the literature around the fear of addiction when administering or taking opiates, but more she also draws on the palliative care concept that suffering pain is unnecessary if it is well-monitored and not allowed to 'break-through' a certain threshold.

Neroli's focuses is very much on experience and training, "the caregivers can't (..) do that. They haven't got the expertise...you've got to have the expertise of the staff there to recognise that that's what this person needs...I think it comes down to that you need the expertise and you're not getting that. The caregivers are wonderful, but they haven't got the years of experience. They don't know

how to monitor someone's pain levels...I've got 35 years experience, I know what I'm doing"

In this way, she works hard to position herself 'above' the care assistants in the (imagined?) caring 'hierarchy'. Her emphasis on training and experience implies that she, like Catherine and Janet, believes that caring is a specialised job. In Neroli's mind the issue of more complex nursing requirements for rest home residents is about a lack of adequately trained staff, which likely to worsen in the future as the numbers of older people requiring institutional care increase (Gomes & Higginson, 2008). However, in another conversation she does acknowledge the value of having time to simply sit and talk to residents, which eases their fear and anxiety. Having time to build relationships and getting to know patients is a vital part of pain management (Henderson, Hanson & Reynolds, 2003). In terms of palliative care, by acknowledging emotional, social, spiritual, and cultural factors, and not just physical symptoms, 'total' pain is interpreted and treated holistically. Again, however, Neroli frames this as being difficult to do because of short staffing and busy routines:

N: umm it's a myth thinking that nurses can have the time to sit with someone that's dying...I guess from (..) the rest home, the thing that really (2) having nursed for far too long (..) I believe that if a patient's dying if they haven't got a relative sitting next to their bed, then they should have a nurse sitting next to their bed (.) or (..) popping in and out on a very regular basis and you should be able to sit and just hold someone's hand and not consider that you're somehow are shirking your job, but that doesn't happen... to be honest with you (.) you know (.) you haven't got time to sit with them...

B: Have you had people talk about [dying] (.) well if you haven't got time to sit and listen I guess you're only guessing

N: You're guessing (1) I mean they fall into (.) there's the quiet accepters (..) and they just potter on (.) and gradually slide(1) There's (.) the (1) absolute avoiders (..) who get angry (..) and then there's the terrifieds (2) and I think the terrifieds are the ones that (..) really (1) upset me because you haven't got time

B: mmm, mmmm. So (...) what do you do? (...) how (...) are they just left to get on with it?

N: Basically if they haven't got a family (..) I mean you can do your best, you can pop in you know, you try to do things, but (.) you know I sound old now, back in the old days (..) if someone was dying, first of all there was the room ((emphasised)) that they got moved to and then generally that nurse was given a much lighter load than everybody else who covered (..) so that that person could spend time with the patient...but I think the problem is the level of expertise of the carers (.) and the carer patient ratio doesn't allow you to do good nursing care ((softly))

B: Tell me what you call good nursing care. What does that mean to you?

N: Ummm (2) to me its not about, you know, the two hourly turns and the pressure area and the toileting and na na na its about taking the time to get to know the person. I mean that's the other thing (...) you know, suddenly someone becomes terminal you don't actually have the time to build up even much of a relationship with them unless they were able to talk and (..) engage in conversation and possibly walk (2) because then they come to you. I mean I've got patients that, you know, I know very, very well, but that's because (.) I can pass them in the corridor and have a thirty second little dialogue while I'm on

the way to do something else. But that, over time, builds up a rapport. But with patients (2) you know you can do all the nursing care stuff, but that's not feeding their soul (1) you know that's just (1) mechanically cleansing their body really (1) and I think that's the difference between the palliative care nurses and, and rest homes is that they understand the importance of actually getting to know the patient and taking the time

At the end of this conversation Neroli appears to have made a complete turnaround from her earlier talk about carers needing to have training and expertise, which perhaps indicates the conflict she feels in her role as a nurse and her role as a caring person. Jill raised this when she was talking to me about caring for a relative. She felt conflicted in that she 'knew' that the person was dying and wanted him to be left in peace to quietly slip away. However, as a nurse she knew that it was their job to come and turn him at regular intervals, with which she assisted. She told me how the nurse on duty joked with her saying, "now you are being a nurse", when she helped and "now you are being a [family member]" when she expressed concern that this might be causing a dying man discomfort.

Caring is "just being there"

On the other hand, Tavae who is not formally trained, expressed no such conflict, instinctively recognising that just "being there" is a great comfort to someone is dying, and making time to do so, as does Lillian whose story follows this short excerpt from Tavae:

T: People die. I remember (...) I had to hold the hands of one old (.) old man I think he's a wee bit scared to go. Was no family there and so I just talked to him and hold his hand (1) and then a few minutes (1) he's gone.

B: And that gave him comfort?

T: Yeah, yeah, yeah

() ((muffled, both talking at the same time))

B: He wanted someone to hold, to touch him?

T: To be there with him

B: [Mmm

T: [And I was holding his hand and just talk to him when he was sleeping maybe he scared to go, whatever

B: mmm, so how long would you have sat with him while he

T: Might be 10 minutes

B: [10 minutes?

T: [10 minutes

B: And did you get the opportunity to do that very often or did you find that you were too busy doing other things

T: Yeah sometimes ((laugh)), sometimes. Because I am working night shift, sometimes we are busy with something. But we (.) the residents come first, the elderly come first, we leave everything and we go in ((softly))

B: You do that, yeah...

T: Yeah. We do that to be there for them ((softly)) ...the people, that's what we there for to care for them...talk to them and share what they (.) I think the love in you can do the work ...like you love your parents that's the way you treat these people (...) as your parents,

B: mmm

T: as your own

B: mmm

T: I think the love in you to see and, and care no matter what (.) what happen, but if we, if there's strong love in you, you can help anything you can (..) aye

The last part of this excerpt arose as Tavae was talking about carers who just worked for the money. She said you can tell who these people are, and they should not be working there if they did not have the right personal qualities, such as love for others.

The joy of caring

Whereas both Janet and Catherine speak about caring in terms of the stress and strain on themselves, in other words caring as a burden, the carers who do not have to 'be there' constantly for their patients tend, like Lillian and Tavae, to emphasise the rewards of caring. The following conversation arose as part of general talk about neighbours just 'popping in' to visit:

L: We still have a fear of death...so we almost sort of try to keep (..) sort of try to protect ourselves and to hide away from it as much as possible. And so when I was aware (1) that (...) the person I was caring for was actually dying and could therefore die on my shift (2) I wasn't too sure how to accept it.(2) Um, and (1) only because I knew that person, and (1) that I was caring for (...) and thought (...) that I wanted to be there for him

B: [Mmm

L: [did I continue (1) And I might say, that to me (...) caring for him as he was dying and being there for him and sharing my life with him and his life with me

became (2) an experience (...) and a joy (...) and an honour (...) that I'm glad I went through.

B: Oh, that's nice

L: And he did actually die on my shift

B: Oh, really

L: And (2) I knew he died because (1) we were still talking only a matter of moments beforehand (...)and (...) I, he, he was talking to me, and we'd shared a lot of things during that time, which I'll refer to shortly. But (1) he was just dozing and then we'd be talking (1) and all of a sudden he looked towards the door and his face lit up with recognition (3) and I looked towards the door and I knew I was by myself, but I looked at the door and I said to him, "you're seeing something that I'm not seeing". And with that he gave his last breath (1) and so, I, his wife having died only 18 months or so before, I, and he was a Christian, I do believe (1) the way he looked past me at the door he did see something that I couldn't see and he wasn't afraid to die. And (1) in him doing that on my shift (2) I just, instead of being frightened by it (1) I just had an overwhelming, just love of life and love of being there for him.

For Lillian having time to sit with the person she was caring for resulted in poignant moments (above and below) that defined her experience of caring:

L: Umm, and I think, going back just a few months from that, when I was on this shift, with him (2) aside from the times that there was mealtimes and times that you had to be (..) sort of preparing a meal or doing housework or whatever (...) and different people had different things that they did on their shift (2) Because I

was on for 8 hours (...) at a time (1) there was a lot of time that was empty, well empty as far as having something that you had to do, so I often spent it, and quite often spent it ((emphasised)) by his bedside just talking to him. And (..) because he came from England I said to him one day (...) “What’s some of the poetry you knew as a boy?” And we were talking about different old poetry that as (.) a schoolchild I was taught and I started to speak about a poetry piece that I just loved (.) and its called *This England* (...) and I started off by saying: “Breathes there the man, with soul so dead, who never to himself hath said, this is my own, my native land” and I looked at him as I was saying it and the next thing he was saying it with me ☺

B: Oh ((emotional))

L: and as a 94 year-old his memories went back to when he learnt it and together we said that poetry. And then he looked at me and he had a grin from ear to ear ☺ and he said “thanks Lillian for that, I’d forgotten it”.

B: Oh, how cool

L: And he said, “I enjoyed going over that again” and that was (..) those sort of moments, and I’d share things like that with him and we’d talk about when he was a little boy and what did you do (1) and sometimes I’d share what I had done during that week. And (1) that (1) that is moments that are precious.

B: Oh absolutely, mmm

L: And, and I believe that’s why I love being a carer because you share your life(1) and its not their life, its not your life its combined and by sharing it (.) you enchant two lives.

B: mmm mmm

L: And (..) you know (1) it was (.) it was really (.) it (.) it's as I said it's a privilege to be carer

B: mmm, absolutely, [mmm

L: [And that's why I s'pose I'm still a carer because ((laugh)), because it really, it is, you know

Kleinman (1988) talks about the benefit or indeed desirability of just being there and simply 'listening' to someone who is dying. According to Kleinman, it is not about finding answers to tricky questions or offering hope in terms of better technology.

Rather at this time in a dying person's life, 'intense listening' and 'empathic witnessing' are more appropriate aspects of care.

Different standards

Janet's recollection of the care that Paul received fell well short of the kind of care and attention Lillian and Tavae gave their patients. The following incident ultimately influenced her decision to care for him at home, for what turned out to be his final three weeks. She told me how the decision to take over Paul's care and bring him home from hospital was a sign from God. Up to that point, she had had only glowing things to say about Paul's care, "the services I had here were just second to none"; she had absolute faith in their GP, "whom I've a very, very high opinion of" and the district nurses were "really wonderful, great girls". Having been asked, "so how did you find the hospital care", she hesitated for a full five seconds as if she was unsure whether or not to tell the story, or perhaps she just did not know where to start. Finally, Janet told this story:

J: (5) Good up to a point, but then I'm an old-timer

B: Now tell me what you mean by that ((laugh))

J: I said to God when I prayed, I said, tell me if you think I can cope with Paul.

Indicate to me if you think I can do it because I don't know if I can or not

((tearful)) And I went down to the hospital (..) and he's sitting in a chair, slumped

over like this ((adopting a slumped position in her chair)), bare feet (..) no

blanket or anything over him (..) pyjama top and trousers (..) bare feet on the

floor (..) and nothing (...) and I took that for me was an indication from God to

say to me take him home Janet, you can do better than this ((crying))

B: Yeah, yeah

J: And, so that's really one of the reasons I took him home

B: mmm, mmm was he able to talk to you much at that stage?

J: ((Sniff)) He was when he was in hospital (..)but after he came home he just

sort of (..) seemed to withdraw a bit

B: Mmm, but he wanted to come home

J: He wanted to come home

B: Yeah

J: absolutely

B: yeah

J: Didn't like being in hospital [at all

B: [Why do you think it was? They were just too busy?

J: Impersonal

B: Impersonal, mmm

J: Um (..) some nurses are better than others you know if you (1)if you wet the

bed you are (1) sort of penalised and that sort of thing

B: Really? in this day and age?

J: Yep

B: ooh

J: So you know from my point of view, in my nursing training,

B: mmm

J: not kosher

B: no, no.

J: So (1) it was good up to a point (..) but only up to a point

B: mmm

J: It's the sort of place that if I had a family member who was very ill (..) I wouldn't want them to be in hospital for very long. The nurses are very knowledgeable, some of them are very, very good, some of them are excellent

B: mmmm

J: But then there's an element that's not so great (..) and some of them are women (..) who are (...) working to augment the family budget (..) not for the love of nursing

B: and you can tell?

J: and you can tell

This was the first criticism Janet had made of the care that Paul had received. From the outset of the interview, she had presented a positive picture of the care given, so it came as a surprise that this experience, which had obviously been very upsetting and marked a turning point in Paul's care, did not surface until nearly half way through the interview. Once this story was told, it seemed to open a floodgate of similarly negative experiences. For example, Janet then talked about how some of the nurses were there

only for the money, talking over Paul's head about their own personal matters as if he was not even there. Similarly, she gave an example of the only time she saw a doctor while Peter was in hospital, just as he was about to be discharged:

J: And he [son's name] didn't like the way the Dr talked over Paul's head, "Well you know he's dying, he's not going to be with you very long",

B: Right

J: and all this sort of thing

B: Right, right

J: And [name] said it took him all his time to bite his tongue ((angrily through gritted teeth))

B: mmm

J: He thought (..) you just don't talk over people like that (..) the man's not confused at this stage

B: mmm

J: You know (..) "Your father's dying, you know that don't you?"

B: Mmm, mmm

J: "Take him home, but if you know have a problem you know we can always take him back in again" and I thought, ooh boy (..) that'll be the day. I'll cope, I'll cope ((angrily))

B: Yeah

J: So (...) that's (..) it sounds very negative about the hospital and I don't intend to be (..) um (..), but (...)

Janet obviously found this kind of treatment abhorrent, comparing it with her two favourite district nurses who approached nursing in the same “no nonsense” way that Janet herself had nursed and had expected nurses under her care to behave when she was charge nurse. Janet’s explanation for the questionable standard of nursing care was that competent staff are often overlooked because of the cliques that form in small towns, with friends finding jobs for each other. She gave an example of this, which was the only criticism of rural living that she made. I have not included the story here, but it reinforced the impression she gave of herself as a professional ‘no nonsense’ career woman, and perhaps explains why, as Janet spoke more about nursing Paul at home, she felt that she needed to be in control of the caring process. Janet had spent the first half hour of the interview telling me how she had raised three exceptionally bright and successful children while holding down a busy working career, in various responsible, managerial roles. In this way, Janet had positioned herself as an accomplished, competent person with very high standards. In the context of the whole interview, it seems more likely that this need to be in control drove her decision to bring Paul home, rather than her childhood memory of caring for dying people at home:

J: My daughter and her husband came down, [name] is a big strong boy and he was able to do a lot of lifting with me ((quietly))

B: Right

J: And [name] and [name] the same, so (..) you know I really didn’t need any (...) any help ((very quiet))

B: mmm

J: And knowing that made me feel about it

B: the fact that you could be in control of

J: Yes, that I could see what was happening. I was in (1) I knew that Paul was getting the best of care because I was doing it

B: Right, yeah

J: And ah (.) so there was nothing sub-standard

Catherine was less critical of the nurses at the same hospital. She felt they were good to her husband, but:

C: I found that they (...) ((sigh)) they're busy (...) put it that way, they're too busy. I used to go down every mealtime and feed him, when he was in there, otherwise he wouldn't have eaten

B: He wouldn't have got fed?

C: No [he wouldn't have got fed

B: [No, he wouldn't have been able to

C: No, no

B: So they've got their routines, and

C: mmm, but Hospice, they have the time.

B: Yeah, yeah (3)

C: This was the difference

To treat or not to treat: Part Three

This also raises the issue, when is treatment care and when is it intervention? Generally, the participants spoke of treatment as 'care' when it was acceptable to them. If it was unwanted, it became an 'intervention'. Obviously, this distinction was made retrospectively. The issue of offering or withholding treatment arose in all of the

interviews, with the participants being divided in their opinions. Based on their own experiences of nursing their spouses, both Janet and Catherine, in hindsight, felt their husbands would have enjoyed a better quality of life, had there been less intervention. However, at the time ‘expert’ advice guided their choices, as well as, in Paul’s case, the will to fight the cancer. In Graham’s case, they had been sent home, having been told “there was really nothing anybody could do because it was inoperable”. A course of radiotherapy had been offered, but when the time came, Graham was too ill to travel to [city].

Jill, who is an enrolled nurse with more than thirty years experience was adamant that people should be allowed to die naturally and that intervention should be withdrawn, especially for people with dementia. A recent conversation with a doctor who had said, “you can’t let a patient starve or dehydrate to death” had prompted Jill to respond to the community notice that I had placed in the hospital. She did not want to have her interview taped, because she was concerned that it could jeopardise her job. However, she approved of the inclusion of quotes from the notes that I took during several hours of discussion with her, having amended what I had written by substituting her own words. With regard to medical intervention, Jill made the following points:

“hospital admissions are treated as acute cases, so they have to be treated ... because some doctors see death as failure...no matter what, patients have to be kept alive”.

However, she personally believed that

“when patients get to the stage of not eating [or] drinking [and] suffering major weight loss they should let nature take its course”...[instead, doctors] try to prolong life, regardless...they keep them going to do it all over again”.

In Jill’s view, “doctors should be thinking more about future quality of life”

Janet also contrasted the negative aspects of medical intervention with quality of life.

In fact, the most upsetting aspect of Paul’s care, as far as Janet was concerned, was receiving chemotherapy. When I asked her if, in hindsight, they would have done things differently, she replied with the following story:

J: I would not have had chemotherapy ((emphatic))

B: You would not

J: Under any circumstance

B: No?

J: ((Muffled, tears)) For me personally and I don’t know what the future holds for me now,

B: mmm

J: but if I have an illness, not under any circumstance will I have chemotherapy

B: Right, right

J: What I saw happening to Paul was just (..) the cure was worse than the disease

B: Right

J: He only those (..) tablets Xeloda I think they were called

B: Now that was after his op, wasn’t it?

J: Well after his op he had the injection down at the hospital, that was bad enough

B: mmm

J: but it was nothing compared with these other tablets

B: mmm

J: Xeloda, X e l o d a ((spelling it out)), Xeloda, and they were just absolute dynamite ((whispered))

B: So did you, when, when he started on that (..) like was there a consultation to say these are what the options are and this is what might happen or

J: Yeah, I suppose there was in a way. My son, who's (..) as I say, my oldest boy who's very smart at those things went on the computer and he got me all, no it was actually [name] who got me all the stuff on the computer

B: mmm

J: and sent it down. And I knew what the ramifications were (..) but it had to be Paul's decision

B: And he wanted to do that?

J: He wanted it because he wanted to live

B: Yeah, yeah

J: And um (4) oh no I think the constipation was the worst thing he had to cope with

B: mmm

J: and sickness

B: mmm

J: because he was constipated he was vomiting

B: Now was this before he went to the hospital

J: Yes

B: Down here

J: Yes. When we were up in [city]

B: Oh, ok

J: We were up there for a fortnight

B: Right

J: 3 weeks, mmm

B: mmm

J: And ah, and then when his hands, I said, "let me have a look at your hands Paul" and he held out his hands and they were blood red, they were (...) more like that ((showing me an example))

B: Oh

J: I said, "oh my God, let me see your feet", his feet were the same. I said "no, no, no, that's not good so I went down and rung the oncologist straight away"

B: mmm

J: She said "stop them immediately"

B: Yeah, yeah

J: So um

B: How long had he been taking them at that stage?

J: Only about a month

B: About a month

J: mmm hmm

B: mmm

J: (2) And they were just (1) dreadful things

B: mmm

J: And like I say I will never ever have chemotherapy

B: Never, mmm

J: When my time comes I'll be very happy (..) just to slip away and I believe that if Paul had never had any chemotherapy (..) he would have longer (...) and a more full life

B: Do you think?

J: I definitely do

B: Definitely

J: No doubt in my mind

In addition, Paul underwent a prostatectomy, not because of the cancer, but because of an incontinence problem:

J: And we had to rush round (...) we knew where every toilet was

B: Yeah, yeah

J: and you had to rush round to go to the toilet (.) um (.) up in the night he had to be up two and three times in the night

B: [Yeah

J: [but always managed to get to the toilet (.) so I just (.) looking back on it think, oh for heavens sake did you really need to do that?... and that was when he became incontinent, you see

B: Oh for goodness sake

J: Yes

B: Oh dear

J: (4) And I washed sheets and washed sheets and washed sheets til I was (...) and it was bad weather (..) I had my dryer on all the time drying sheets and (.) draw sheets (.) and all sorts. It was (.) very (...) very hard ((quietly))

B: Yeah

J: and they should never have done the prostatectomy

B: No, mmm, mmm

J: Yeah. (4) He was only in for a couple of days into the bargain

B: Yeah. And then they send him home for you to look after, mmm

J: Yep ((matter of fact)). It was not, not good at all

Thus, Janet's opinion, medical intervention compromised Paul's quality of life, as well as her own. She went on to tell me that she would have preferred that Paul did not have the second round of treatment. She had wanted the whole family to go away on holiday together to Australia, to enjoy some quality time with their Dad. Her sons however, were intent on doing all they could to find a cure. One son spent time on the internet researching cures and offering to pay \$1000 a month for unsubsidised drugs that might help. Janet could not understand why her children could not accept that their father was dying and would not let him go, illustrating the conflicting points of view that can arise even within the same family:

J: I said boys (...) this is just nonsense

B: mmm

J: Your father's going to die ((quiet))

B: mmm

J: And they came in here and (...) I had that sunroom there was all set up you know, for a dining area and it was all very beautiful, sort of doors open and things like that. Oh the boys decided they were going to set up Dad's railway ((louder)) (4) They came in here, my dining room table's in the shed ((laugh)), my chairs are scattered everywhere, the model railway stuff, which [name] is trying to get rid of for me, everyone was trying to do things for Dad and all they needed to do was just accept our Dad is not going to live ((quiet))

B: Yeah, yeah

J: So what we want to do is to give him some quality time

Janet and Paul's story shows how medical advances can have the unintended consequence of prolonging life at the expense of their quality (Shapiro, 1997; Lawton, 2000). Further, Wright et al. (2008) suggest that while patients who receive aggressive medical interventions may have a worse quality of life in the final weeks of life, their caregivers also suffer worse quality of life outcomes. Conversely, caregivers of patients with a high quality of life are better prepared when death comes and experience less regret. It seems that although the prospect of a loved one dying is upsetting, witnessing a drawn-out period of decline and confusion or social disengagement is only adds to the distress. One of Janet's most upsetting recollections was Paul saying to her, " I think I know you. Who are you? Oh yes you're my wife, aren't you?"

To treat or not to treat: Part Four

However, Tavae had a different story to tell about medical intervention. Like Jill, this story was the catalyst for her participation in the study:

T: Yeah, I saw some, aaah (2) some in the news about people about the parents got that, what you call that thing? (..) they can have a right to kill

B: Oh, euthanasia

T: [Yeah, yeah that's right

B: [Yeah?

T: And I experienced the (..) with some people in the old, here in the home

B: mmmm?

T: They said in the hospital (1) they prefer not to treat them (.) because they are old

B: Right

T: That's the thing, I thought I had to speak up those sorts of things, over eighty (too)

B: mmm

T: because I had experience with that part of the thing

B: mmm about not treating?

T: [Yeah, yeah,

B: [older people

T: Yeah, they is too old, wasting the medication

B: Yes

T: And I say (.) "you're the doctor, you do anything you do for those people", this is aah, they work hard in the community

B: Ok

T: And they say, now she is too old. What, I'm talking for one person I

B: [One person that you cared for?

T: [was too old

T: Mmm. Yeah I was care for it

B: Mmm

T: and she had a fall (1) and broke the wrist

B: Mmmm

T: And that was why she was (...) pain, something like that

B: Now, was she in the rest home?

T: Yeah, in the rest home,

B: when she had the fall?

T: mmm hmmm

B: And then she went into hospital?

T: Yeah, and the, and the (.) girl rang the doctor, ah on duty,

B: Yes

T: she said “ring the ambulance and send the lady into the hospital”

B: Yes

T: And when they (.) I came in on the night shift and the girl left, the nurse left

B: Yes, mmm

T: and then the doctor rang she's gonna send back the lady, that was after 11

B: mmm

T: and I said “why you send that we send there, because she was screaming of the pain”

B: mmm, mmm

T: and she said “we not wasting the medication for people like her” (...) and I was really really angry and said “that is your job”

B: mmmm

T: “you have to treat her”. And she said “I am going to send her back to the home” and I said, “no, no no, you do it”. He said “what you want me to do?” that what the doctor said. I said “you are the doctor. Give her some x-ray the wrist”. I told her “whatever you can do to help the lady” and I was argue with him. He said “we don’t wasting the medication in these, people like her”. She was nearly 90, or so. I was very shhh angry and I argue with him and ask she stay over. And then he said “I will keep her here but I am not doing anything to her”. I was really angry at the time

B: But did they not put her wrist in a cast or anything?

T: I don’t know what they do overnight and in the morning that’s what he said. “We gonna keep her here and I’m not going to do anything to her”. So that’s why I said it is “you should do something about this, she pay her tax, everything, she old” and he said “I am wasting the medication, wasting the (...) medication or whatever to treat a person like her

B: Mmmm. And was she just old or

T: Yeah I think she had the complicated in the, in the (...) but the reason why we sent her, she was out with the family for lunch (...) the only reason because she had a fall (...) and she was screaming of the

B: [The pain

T: [Of the wrist, yeah, and that’s what the doctor on duty says, ring ambulance and send that’s the idea (muffled) don’t send her she’s dying. I said she was out with the family and the only reason why we sent, because she had a fall and that was what I thought to myself, what sort of health? I even went to see the medical, what’s the man ah?

B: The manager?

T: The manager, and talk and express my concern and angry

B: Mmm

T: And the same story, is that we can't do anything and (.)

B: Did she come back to the rest home?

T: No she died in the next morning (1)

B: Oooh

T: What he said is not doing anything, we just keep her here overnight

B: And then she died

T: And then she died. I was going to go (...) and talk to the family. I have no right to

B: Mmm

T: but I thought oh well.

B: Mmm

T: I got a letter, a apology from the, whatever, those people,

B: [From the hospital?

T: [from the hospital (..) and I said, I rang again from the nurse ah (.) whatever, head of the nurse. I said I'm not accepting that apology I'm going further, but I (..)

B: But you didn't

T: But I didn't

B: No

T: I even called the [local paper] and expressed my angry (.) my anger. But they only listen to the (head) people

For Tavae it was shocking that the hospital would not want to treat this resident. She felt that no matter what, an older citizen who had paid taxes all her life deserved treatment, even if she was nearing the end of life. One of the rewards of caring for older people that Tavae mentioned in another conversation was being able to share in their wisdom, indicating the respect that she felt for her elders, who because of their longevity have much to offer society. On the other hand, Jill believes that “some decisions [not to treat] are easier to make because of their age”. These two perceptions highlight the difference between two cultures, where the Western view is more likely to be that the death of an older person is dying at the ‘right time’ and therefore it can be acceptable not to intensively treat that person (Kastenbaum, 2007b).

Zafar, Alexander, Weinfurt, Schulman & Abernethy (2009) highlight the complex decision-making process with regard to cancer treatment and quality of life. Looking at the problem from both perspectives, medical and lay, they found that physicians make their decisions based on factors such as stage of disease, co-morbid illnesses and patient’s age. Patients and family, often not fully understanding the implications of prognoses and treatment options initially tend to accept greater risk for lesser benefit. They suggest that this often changes as time goes by, as Catherine’s earlier story suggests. However, to date there have been few prospective longitudinal studies that can confirm this.

Dying is natural

Tavae mentioned several times throughout the interview that people think euthanasia is the right choice because they cannot bear to see loved ones suffering. However, in her view, dying is a natural process. It is not the people who are dying that are suffering;

rather, the people who visit and do not understand what is happening are the ones who are experiencing emotional pain and anguish:

T: And then another thing what I notice about it (..) the people who are dying () ready to die (.) They are not suffer (.) They are not suffering like aaah (..) ((I think what Tavae is saying here is that the noises people sometimes make in their sleep are not necessarily indicative of pain or suffering)) It's the family (.) it's the people leave who are suffer

B: Yeah

T: because they come and look. The people are comfortable in their bed, they wanna sleep they want something like that

B: Mmm

T: but it's the people (.) the family who come and see and wish (..)[but] they have no time to stay there longer

B: [mmmm

T: [and watch them die or watch them feel comfortable and talk to them.

B: mmm

T: They just come and say oooh is she ((muffled)) Oooh is she, something like that? They don't even stay for half an hour or (..) even (..) they just come and see when she died (...) things like that

B: So do you think (.) why do you think that is? Is that because they are too busy?

T: I think it's the busy or whatever ((muffled))

B: Or is it because they feel uncomfortable?

T: Oh yeah (..) I think they feel uncomfortable. Looking at the person

B: mmm

T: I mean in the mind too (..) They can't handle it

B: They don't know what to say

T: They don't know what to say. They don't know what to deal with it. With the stress (..) of coming and look at the (..) at someone is sleeping there, they can't talk to them and things like that

B: Do you think, you know if someone could say to them you can just sit there and hold their hand, do you think they would

T: [Yeah

B: [do that?

T: Yeah I think, some they just too busy, they might be just () (..) even if they come and sit and (..) and (..) and try to feed or something

B: mmm

T: they have no time

B: No time, mmm

T: Some, some are alright

B: Yeah

T: but most of them are

B: Yeah

T: They have no time, they just come and see and they say (.) when she will go?

B: mmm, mmm

T: But aah I don't think the people to me (.) the people (.) the people are ready to die (.) they are not suffer

B: mmm

T: They lie there (.) they must be comfortable

T: This one they said my Mum is suffering (.) why don't you do something about it?

B: mmm

T: In a way like that because is not (.) the person is not suffer it's the one who look at it

Tavae's perceptions are once again an indication of the conflict people feel about the dying process. On the one hand, she advocates intensive treatment right to the end because elderly people deserve to get the 'best' care they can, whereas on the other hand she perceives dying as a natural process. Usually, when people talk about dying in this way, they support a non-interventionist pathway of care.

A time of transition

The notion that dying is a natural process has only comparatively recently come back into the dying discourse. For many years, and probably most of the lifetime of these participants, death and dying was medicalised and hidden from their view. Now that it is moving back into their lives, the participants' stories demonstrate a lack of knowledge about dying the 21st century way, which is compounded by living in a community that is not well resourced to support all aspects of the dying process. Neroli discusses this in the following story, which concludes the chapter. The story has been edited, for the sake of brevity, however the material that I have omitted does not detract from the overall meaning:

N: Now here's a good story for you. [township] (...) and a lot of these places, they have doctors there Monday to Friday. Doctors have changed. They used to own their practices and (1) were there for years. Now they're employed under contracts by the (1) DHB I believe. So, there's no incentive there for them to do anything more than what they're paid to do. And, you'll find that they're often away (.) either on conference leave (.) annual leave (...) whatever leave. My partner is a locum GP. He goes to cover for these doctors so they can have a break. This last week he did a Thursday and Friday in [township]. He was looking after a lady at home who was in the terminal stages of cancer. Ummm, (1) he spent about 3 hours trying to track down the District Nurse because she was the only one who had the morphine pump in [township], but she was away at the time. Then called in an off duty prime nurse who knew how to get hold of the district nurse because she knew where she'd be. They finally managed to get the pump, not that the lady needed it right then, but he knew the weekend was looming and he didn't want her to (2) be suffering. So everything was put in place so the weekend nurse could set it all up. The lady died on Friday evening (2) The doctor had finished work at 5 o'clock, and she hadn't died before he finished work (2) The undertaker could not remove her body from the house because nobody had signed a death certificate. The family wanted the body removed, because [] and there were younger children there. And from their perspective it wasn't appropriate to have Mum lying in the house (2) I think in the end, after an awful lot of trauma to the family, as you can imagine, the nurse, because at the weekend there is no Dr, (.) there's a nurse and there's a doctor doing telephone back-up (2) but that can be from all over the place. Umm, so the situation was the poor nurse, who was also a prime trained nurse

who was also meant to go up to [place] for someone having a heart attack and you know all over the show, was also trying to chase up a doctor somewhere who could sign the certificate, so that the body could be removed. Now the stress for that family (2) was absolutely incredible (..)

B: mmm, at a time that was already stressful

N: And the other thing was, that although they knew that she was going to die, everyone knew that this woman was terminal, no plan had been put in place because of course a doctor can't sign a death certificate before someone is dead. So they had this lady, so I think finally the undertaker, he picked her up on the Saturday afternoon, she died on the Friday evening, and he drove her body to the nearest doctor who I think was in [township] from [township] to get her certified dead.

B: So that's a good, well is well over an hour isn't it.

N: Now the other thing is, that will be an expense to the family (4) on top of everything else. And that's not to say the nurses didn't do everything they could. The doctor did everything he could, but (...)

B: But if you fall outside of the

N: Yes and this quite often happens... but at the end of the day you have situations with the terminally ill where (..) at the weekends

B: mmm. So now, I'm guessing that it was the family's wish to have Mum at home, they wanted her [to die

N: [They wanted to, yes she was a Māori lady and there was a lot of family there and they wanted her to die at home. But they didn't want her body there once she had passed away

B: Even, because that would be unusual wouldn't it for a?

N: Yes you'd think so, but then again there's all different levels of, especially in the [] Island (.)

B: Yes you can't assume

N: No

B: No you can't assume

N: And I think because, I think the youngest child was sort of around 9 or 10 they wanted (.)

B: Yes, and their wishes needed to be respected, yes

N: Yes

B: So nobody (...) perhaps told them what could happen, do you think there hadn't been enough discussion prior to

N: Probably not, but even if they had told them (...) the reality was that if she died on a Friday afternoon (1) after 5 o'clock (2) there was a strong chance that there was going to be a problem for them although that probably wasn't explained to them

B: And I guess that would be a very difficult thing to sit down and tell somebody that wouldn't it

N: That's the nuts and bolts stuff

B: Yes, and you don't want to be doing

N: No

B: No. People don't want to be hearing those sorts of things.

N: No

B: Gosh

N: So that was quite a

B: And that was traumatic for everybody, for the family, for the health professionals for everybody

N: For everybody. Very frustrating. And also just finding (.) I mean I think umm, it took about two – two and a half hours to locate a morphine pump in [township]. There is only one and the district nurse has it. And if you can't find her (2) So our parting shot was maybe they should ask for somebody to fund a pump for the surgery because there needs to be more than one

B: I was going to say there needs to be one in the surgery...

N: Yeah, they're not expensive pieces of machinery and (1) you know, its like every surgery has an emergency child birth kit. They may never use it, but you still have it there.

B: Because things have changed haven't they? This is something that I'm really interested in, is the change now from so-called dying in a hospital, which is what was happening maybe twenty, thirty,

N: mmmm

B: forty, fifty years ago that's where people died and now there's this move back to people dying at home. Do you think we are quite prepared for that? Have we got

N: We haven't got the support services to deal with it. If you are somewhere like Wellington, the palliative care is absolutely fantastic. Ummm (1) mainly through the hospice (1) so if you're dying of something other than cancer I don't know if you fall through the gaps or not.

B: I think they're getting, they're do I use the word better?

N: Spreading the net further.

B: Yeah, yeah, there's more umm respiratory and heart patients, yeah actually going to hospice, but it is, it's a huge percentage cancer...

N: but again its still seems to be the family's responsibility to find out what help is available for them, rather than a person being put in charge of organising the support...whereas when we are born, it all just gets thrown into action doesn't it?

B: Now this is really interesting, because this is something that I've had in the back of my mind, because I liken the EOL care, especially the home dying, to the home birth movement. I can see parallels there and the amount of support that there is for young mothers and parents it seems at the other end of the spectrum, we don't have that support for people. There are no umm, well, what do you call it, ante natal (.) there's no ante death class is there?

N: No

B: So how do we learn those things, you know

N: I can remember when I had my children I was overwhelmed by, you know the pregnancy test was positive and suddenly you had blood tests to do on Tuesday, you had an ante natal appointment, you had the midwife visiting and it was all just, it just all got organised for you

B: mmm

N: And apart from the occasional telephone call you didn't even have to do anything, because everyone was running round making sure everything was done

B: mmm

N: Whereas (2) you know people don't even know what their rights are. I was thinking after this lady was you know not being able to have her death certificate

signed and I was thinking very morbid thoughts and I thought if anything had happened to my children when they were younger I would not have let them go, I would not have wanted anyone touching their bodies except me. But I don't know whether legally you're allowed to keep a body in the house. I don't know if you have to legally have an undertaker. I don't know if (2) I don't know what the legalities of it all are and I've been working in this profession forever!

B: mmm. And if you don't know, how is ordinary Joe Blow supposed to know 😊

N: And I think most people just know what the undertaker tells them. But actually they're the salesman in this situation!

B: Yes, yeah

N: You know, its like going to the garage and just believing your mechanic when he says you have to have four new tyres, really

B: Yeah, I mean what, I guess if you think about it, what's the worst thing that could have happened to that undertaker if he had removed the body? Is someone going to send him to jail for doing that 😊

N: Well unfortunately, ever since that lady sort of was embalmed and wasn't dead yet

B: mmm

N: But that's the other thing, and this might be a little bit, it's a symptom of the whole thing, do you have to be embalmed? Umm, what, what are the legalities of what actually has to happen to a body in this country?...But why is it that when babies are born, we all know they have to have this checked and that checked, but here you and I are sitting here, obviously both over 25 and we don't even know what (2) that whole (2)

B: mmm mmm. Because it has become professionalised

N: Other people just take it away

B: Yes, and we've got used to other people dealing with it, so we haven't had to think about it too much. It's a good point, mmm

N: mmm, a morbid point. Well no, because it could be very empowering as well, I mean

B: Yeah, yeah (4)

N: It's the great unknown isn't it?

Neroli tells a story about a lack of resources and co-ordination of services in a rural area. However, more than that, she draws a parallel between how society treats death compared to birth. These are two supposedly 'natural' events in a person's life and yet there is far more emphasis on resources and education for expectant parents than there is for people who are dying or caring for someone who is dying. While this suggests that we are still living in the shadow of a society where death and dying was taboo, it also echoes O'Reilly's words from almost ten years ago, that, "dying care, like birthing care, should be available where people want it, and that it should be quality care wherever it is given" (2000, p. 16).

Although we might want to reclaim death as a natural part of life, dying has become a complex, technologically managed process. In this respect, the people in this study are poised between two different paradigms of care for dying people. In other words, their 'personal troubles' reflect a particular socio-historical moment (Mills, 2000). In the first instance, dying has moved back into the community, with care increasingly being provided by the community (Heaton, 1999). I am not suggesting that people do not want more control of a natural process that was once part of everyday life. However, the

stories presented here tell us that people are struggling with changing contexts for dying, at home, and in residential care. Traditional support networks no longer exist in the way they once did, the dying phase is lasting longer, symptoms are more complex, medical technology has improved, and with that comes an expectation for a kind of care for which most carers do not have the life experience, the knowledge or the skills to provide. Although Hospice New Zealand offers a Palliative Care for Care Assistants course, the uptake and implementation of this ‘specialist’ knowledge is limited (Latta, 2007), as is the information and training offered by various carer support groups in the community. Despite continuing requests for more information, education and practical support for people who are dying and their carers (Phillips & Reed, 2009), there is no modern equivalent of *ars moriendi* embedded within the fabric of society to guide the actions of today’s lay carers.

As a result, the participants’ stories convey a certain ambivalence towards EOL care. On the one hand, a caring ethic has been a lived experience for them, learned as a part of growing up. On the other hand, they have little experience of dying in today’s world, a part of life now perceived as requiring specialised care, and best left to the experts. Thus, on the one hand, they want traditional, empathic ways of caring, but on the other hand, they want and expect the best of medical care. In order to create a balance between the two worldviews, lay carers will need to work at creating and maintaining partnerships with health professionals. Otherwise, it is likely EOL care will remain a specialised field, albeit in a more visible way.

For most of us, death and dying has been relegated to the back of our minds. Yet, none of these women felt uncomfortable speaking about death and dying. This was one of the

'pre-prepared' questions I had asked each participant, that in the context of the whole interview elicited little response. According to their carer wives, the dying husbands were able to discuss their impending death and to make their wishes known. The carers who cared for the general public acknowledged that everyone is different, but in general it seemed to them that people who are dying do not have a problem speaking about it. In this respect, they did not support the 'denial of death' thesis. Rather, anxiety is probably a better explanation, which is associated more with unknown factors around the dying process than death itself. Most people have had little recent experience of another's dying from which they can learn. This was certainly my own experience as a carer.

Summary

To summarise, these carers' stories contextualise the complex experiences of older rural people, receiving and providing EOL care. Although the participants spoke about similar issues, such as the physical demands of caring, a lack of specialised knowledge, and intervention versus quality of life, how and why they spoke about these issues diverged, depending on their own particular standpoints. By comparing and contrasting the stories, while at the same time organising them thematically, two main themes emerged from the analysis: the different constructions of caring and the social location of decisions about how to care.

Caring

Different caring roles, as well as the extent of previous caring experience, informed the participants' views of what caring entails, creating multiple and diverse perspectives. The most conflict arose regarding when to continue and when to stop medical intervention. In addition, Janet and Catherine's experiences in particular, highlight how

complicated and conflicting just one person can find the experience of caring. What clearly emerged however, was how meaningful the values of empathic and compassionate care were to all of the participants. In the hospital and the rest homes, the nurses felt frustrated that they are unable to provide the kind of care that they would like to provide, while family carers' felt that their loved ones were being neglected. The nurses cite several reasons for this, including understaffing, and increasing administrative demands. Although families might sympathise with this to a certain extent, they still find it distressing to see their loved ones remaining unfed, or waiting to be toileted or showered. In general, the participants express a preference for 'comfort care', which means having time to sit and listen to people, getting to know them and assessing their needs as people rather than according to their disease.

This raises an interesting issue: what is care? Is it something that professionals provide, or is it something that loved ones provide? Can it be both? It appears that as nursing and medical staff become more highly trained the answer to this question changes, suggesting that a hierarchy of care exists, which influences the decisions made. This is where a patient-centred model of care that is consultative, incorporating patient and family wishes, and offering informed choice goes some way towards achieving well-managed (Kellehear, 2007) and appropriate (Pattinson, 1977) dying for all concerned. However, as the stories here have shown there can be opposing opinions just within one family. This makes it very difficult to decide upon the best course of action for all concerned, but at the same time it highlights the problems of adopting a one-size-fits-all approach (King & Quill, 2006). Caring requires the recognition of difference, which takes time and involvement (Frank, 1991).

A report from the Institute of Medicine (2001) states that patient-centred care, which is respectful and responsive to patient needs and abilities to make decisions, is quality care. In this vein, Branch (2000), MacLeod (2000; 2001) and Lloyd (2004) all talk about caring in terms of having empathy, compassion and respect for others. Branch in particular describes the need to build and maintain therapeutic relationships. This, he argues, is best achieved by getting to know patients, trying to understand their viewpoint and background and then negotiating a plan for care, together. Buetow (2005) conceptualises this kind of relationship in terms of co-providing, whereby physicians, patients and their caregivers have equal input. While a more balanced relationship is desirable, it seems unlikely that equal relationships would be common, or even if all patients would want this. Older people in particular tend to have high regard for professional opinion. However given time, relationships can be built based around mutual trust and respect. Unfortunately time, it would seem from the perspective of the participants in this study, is something that is lacking.

Moreover, MacLeod (2000) argues that as part of their training and medical socialisation, medical students lose the compassionate attributes that led them into medicine in the first place, learning instead to be professionally and emotionally detached. One of the nurses in this study touched on these issues, identifying detachment as a quality necessary for her personal emotional safety. She said that she is always too busy to attend any kind of 'debriefing' session after a person's death, and furthermore it is difficult to get everybody together, because the nurses work different shifts. Although the hospital where she works offers individual counselling, she just never gets around to taking up the offer, preferring to work through issues on her own, or taking a holiday when she 'burns out'. In addition, several participants argued that

caring, in an empathic way, “is not something that you can learn”, but is something that you ‘have’ ... “the love in you can do the work”.

Social location of caring

The stories told by all of the participants demonstrate the multiple experiences of rural EOL care. From an institutional or organisational perspective, this kind of complexity makes providing the sort of rural EOL care that will meet everybody’s standards and expectations very difficult. However, understanding the social location of people’s needs will help us to respond to this complexity at an appropriate level.

It is widely known that rural New Zealand communities, particularly the smaller towns, have suffered from economic restructuring and down-grading of services over the last twenty-five years (Chalmers & Joseph, 1998). Healthcare services in particular have been affected. For example, rural areas experience difficulty in recruiting and retaining health professionals, including GPs. As a result many practices rely heavily on locums, which impacts on continuity of care, hindering the formation of therapeutic relationships. Even if there is good rapport with a GP, moving to out of town specialist care disrupts and sometimes ends that relationship, which is upsetting for patients and their families. Catherine spoke about this, and especially the endless visits to different specialists for each part of the body, none of whom spoke to each other about the ‘whole’ patient.

A lack of specialised palliative care knowledge and resources, impact on the quality of EOL care that is able to be delivered, sometimes adding unnecessary stress to the provision of care as Neroli’s example of searching for a morphine pump showed.

Labour shortages also make it difficult to fill carer roles for home support and in rest homes, placing an extra burden on those who are already carers. In addition, the mobility of younger people and more transient families means that the traditional family and social support networks that once existed are slowly eroding and older people are increasingly “bowling alone” (Putnam, 2000).

Older rural people are often stereotyped as a resourceful and hardy lot, who look out for each other and do not need help from ‘outsiders’. Certainly this is the impression that Catherine gives, and although Janet accepts help from her neighbours, she too is reluctant to accept assistance from service agencies. However, this may be due to personal characteristics as much as ‘rural-ness’, therefore it is misleading to make such generalisations. In addition, resourcefulness is sometimes a matter of necessity, as in Catherine’s example of retrieving her car. Rural people rely on being able to drive in order to access health services. However, as they get older, those who are ill or can no longer drive have no choice but to negotiate other ways of accessing out of town appointments.

Although positive stories were told, the narratives in this study were mostly focussed around problematic experiences of rural EOL care. Some of the issues were about EOL care in general; others were specific to rural care. Issues specific to rural EOL care included the need for specialist palliative care in the local hospital and rest homes, the need for 24 hour carer support at home, the difficulties of caring for people with complex needs without adequate training, information and support, and the problematic assumption that all rural people have supportive social networks. In effect then, while EOL caring in a rural community raises similar issues to those experienced in an urban

setting, rural care is further complicated by the nature of the community itself, or in other words the social location of rural living. Add to this, the particularity of older people providing care for other older people and the stories become even more complex.

It is only through sharing stories as we have done here that we truly begin to appreciate the rich diversity and contextual detail of the lived experience of rural EOL care for older people. Highlighting both the divergence and the convergence of these stories, rather than looking for universality, clearly shows that it would be a mistake to think of older rural people as a homogenous population in terms of planning EOL care in the future.

The narratives I have presented are but a fraction of the material collected. I have selected and interpreted the women's stories that I found insightful and re-presented them in the hope that other audiences will find the same. As a *bricoleur* I have stitched together an overarching story of the experience of rural EOL care for older people, that incorporates and I hope authentically re-presents the views of the participants. My own experiences as a carer of an older person have also informed the process, from start to finish. Another researcher, with a different viewpoint could just as easily have attended to different narratives to construct a quite different 'story' of their own. To this end, I have deliberately included large 'chunks' of text in their entirety, re-presenting as closely as possible the original conversations, to show how I have understood the text. In addition, the length of these excerpts or stories suggest not only the salience these topics have for the women, but also the therapeutic value of being able to talk freely to someone outside their circle of friends and family. However, it is entirely possible that

other readers will formulate alternative interpretations, based on their own experience of EOL care.

Limitations

The most obvious limitation of this research is that it does not directly represent the people for whom the study was originally conceived. That is, people who are dying. In this respect, the stories included here can only be viewed as the words of surrogates in so far as they are the carers' interpretations of what they think the experience was like for the people they cared for. In this way, although the carers provide insight into the lived experience of caring for someone who is dying, this has moved away from the original aim of the study. Secondly, it could be argued that the participants in the study do not truly represent the rural population if we think of rural as being isolated.

However, every participant lived in a town that had limited specialist EOL care services and had to travel at least one hundred kilometres to reach a major hospital.

Thirdly, in the initial interviews especially, my interviewing technique may have discouraged the production of significant narratives. For example, when listening to the recordings and transcribing the interviews I noticed many instances where I cut off a possible story by interjecting or following my own train of thought rather than listening deeply to what was being said. At times I also inadvertently "put words in their mouths", which again is indicative of poor listening and a novice's interviewing technique. However, as my technique improved I feel that I got better at recognising a story in the making and working alongside the participants to construct meaningful narratives. Finally, it could be argued that the participant sample was biased, in that they had volunteered to take part after reading an article that implied that their input could make a difference, in other words, improve future EOL care. Because of this, the

women came to the interview situation forearmed with particular agendas. However, these were their stories and as such, they form part of the diverse experience of providing and receiving EOL care.

Future research

In the words of Richardson & St Pierre (2008, p. 476), “a postmodernist position does allow us to know “something” without claiming to know everything”. In this respect, this study did not aim to discover a universal phenomenon, but rather to privilege and thus contextualise the lived experience of rural EOL care for older people. However, a larger, nationwide study would be more influential with regard to future EOL care planning for a population of people, about which little is known, yet predicted to dramatically increase in the future.

Implications of this research

While it seems presumptuous to make recommendations for future EOL care for older rural people, based on such a small sample, the insights and experiences of these women constitute valuable knowledge. How this knowledge might fit within the bigger picture is discussed in the final chapter.

Chapter Seven:

Conclusion

“How people die remains in the memory of those who live on”

Dame Cicely Saunders

In conclusion, I return to something that was written forty years ago. When she wrote *On death and dying*, Elisabeth Kübler Ross (1969) imagined a future where dying would be part of living and care of the dying an integral part of family and community life. Around thirty years later, Ira Byock (1997; Byock, Norris, Curtis & Patrick, 2001) had a similar vision, stating that dying should become a valuable part of community life with family members and friends taking back the responsibility of caring for its dying members. These sentiments are implicit in the WHO's definition of palliative care, which guides the international development of palliative care services. In New Zealand, Hospice promotes 'living every moment', which includes being at home if this is a dying person's wish. In addition, the promotion of 'ageing in place', is likely to increase the need for close relatives, family members and friends to provide care and support in the community as well as driving up the need for more complex care in rest homes.

These are laudable ideals, however, as the stories here have shown, providing palliative or EOL care for older rural people in their own community is a complex issue. People come from diverse backgrounds, with diverse beliefs, attitudes and expectations, let alone physical needs. While having the opportunity to care has its rewards, this study shows that it cannot be assumed that people have the knowledge or skills to care; that they want to care; or even that someone will be available to care. In addition, the context and expectation for providing care has changed. Is it reasonable to offer the possibility of home death knowing that illnesses have become more complex and care has become more technically advanced, moving beyond the realm of what lay carers are able to provide? As the stories here have also shown, there is still some way to go to get services right for the people who are dying and to provide adequate support for their

carers. Can education and training alone address the shortfall in expertise? Furthermore, what is expertise?

There is some ambiguity as to what constitutes good EOL care. Is it specialised medical intervention or is it old-fashioned time and touch? Should it be a blend of both and if so how can this be achieved? While dying at home is the preferred choice, the majority of people continue to die in institutions, and it seems likely that this will increase, rather than decrease. Therefore, perhaps more of the family-oriented style of caring, with the things that people value about home deaths should be incorporated into institutional care.

It seems that this study has thrown up more questions than it has answered. It is unlikely that there will be any simple solution to these dilemmas any time soon, however, it is important to keep a dialogue going between everyone concerned with EOL care: patients, carers, service providers and health professionals. Narrative research is one way of doing this, especially because of the rich, contextual dimension that it adds to our understanding of different experiences. In this way, the major contribution that this thesis makes is that it adds material to a larger quilt of knowledge about rural EOL care for older people, which will always be in the making.

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Appendices

Appendix A

Volunteers needed to talk about end-of-life care

What? I am interested to find out what the experience of end-of-life care is like for rural people.

Who? I would like to talk with people over the age of 65, who have a terminal illness, and who are currently living in the Waitaki district.

Why? I have chosen this topic as part of the requirements for my Masters Thesis in Health Psychology because not a lot is known about end-of-life care from a rural patient's perspective. Telling your story may help others in the future.

How? I have some questions I would like answered, but this is your chance to tell me your story.

Where? You can choose where you would like the discussion to take place.

Time? About one hour.

If you think you could help with this very special project, please phone:

Barbara Horrell

Masters Student (Health Psychology)

School of Psychology

Massey University

0800 167 266

This study has ethical approval from the Lower South Regional Ethics Committee.

Appendix B

VOLUNTEERS NEEDED TO TALK ABOUT END-OF-LIFE CARE

What? I am interested to find out what the experience of end-of-life care is like for rural people.

Who? I would like to talk with two groups of people:

- people over the age of 65, who have a terminal illness and who currently live in the Waitaki district **and**
- people who, in the last eighteen months, have cared for someone with a terminal illness over the age 65 who was residing in the Waitaki district.

Why? Not a lot is known about end-of-life care from a rural perspective. Telling your story may help others in the future.

How? I have some questions I would like answered, but this is your chance to tell me your story.

Where? You can choose where you would like the discussion to take place.

Time? About one hour.

If you think you could help with this very special project, please phone:

Barbara Horrell

Masters Student (Health Psychology)

School of Psychology

Massey University

Phone: 0800 167 266

This study has ethical approval from the Lower South Regional Ethics Committee.

Appendix C

[] Herald Article

Dying Well

Although stories and images of death and dying confront us almost daily in the media, it is not until the experience moves closer to home that most of us start thinking about how dying affects us personally. Perhaps this is because for much of the twentieth century death and dying was a topic not easily broached. For varying reasons, the subject of death had become “hidden from view”, if not taboo. However, times are changing and over the last half decade, social scientists and health professionals have become increasingly interested in researching death and dying, creating a body of work with the aim of improving the experience of dying for all concerned. This is often spoken of in terms of “dying well”.

At first glance, this term may be considered an oxymoron, but with further reflection, we realise that this is what we all wish for ourselves and those we love. A commonly expressed wish is that we will fade peacefully away or die in our sleep. It is common for family members to seek assurance that death was quick, or that the deceased was not experiencing pain or discomfort and certainly not alone.

It is only comparatively recently that I personally experienced caring for a terminally ill person and it was the stories that people told, about their own experiences, that gave me some idea of how dying was done in the 21st century. Almost everyone had a story to tell about their own situation, or that of someone that they knew. I became increasingly intrigued with the potential that these stories have to comfort and to inform as well as helping dying people to understand and adapt to bodily changes and changing relationships with others. This notion is reinforced by the number of autobiographies and stories appearing in books, magazines and on the internet, written by people who have ‘been there’ and want to share their experiences in the hope that it will help others.

Undertaking my Masters Thesis in Health Psychology has provided the opportunity for me to explore how such narratives might assist with the planning of end-of-life care and ultimately dying well. Early research into death and dying was carried out from the

point of view of professionals, concerned with how they could improve their treatment of dying patients. This then moved on to how health professionals could 'help' patients and their families cope with dying, bereavement and grief. More recently there has been a move towards obtaining patients' and carers' perspectives by including their views in the research about themselves.

My research takes this latter approach, focusing specifically on the challenges, and opportunities, of providing end-of-life care in a rural context. As very little is known about death and dying from the perspective of rural patients I am seeking volunteers to help me to understand their experience of end-of-life care. I would like to talk with people over the age of 65, who have a terminal illness and who currently live in the []. I would also like to talk with people who, in the last eighteen months, have cared for someone over the age of 65 with a terminal illness, who was residing in the []. By giving rural people an opportunity to describe their point of view in a brief interview, the study aims to be of benefit to the participants, as well as future patients and carers.

Although there are particular issues regarding rural end-of-life care that I am interested in, my intention is that throughout the interviews people will be able to tell their own stories, in their own way. I also hope that the research participants will make suggestions or recommendations for implementing future care. In this way, the study is designed to be collaborative, in the belief that the insights of patients and carers can make a valuable contribution to future health service planning and social policy. This study has approval from the Lower South Regional Ethics Committee.

If you are interested in helping with this very special project, please contact:

Barbara Horrell

Masters Student (Health Psychology)

School of Psychology

Massey University

Palmerston North

Phone: 0800 167 266

Appendix D

Information Sheet Talking about end-of-life care

Thank you for expressing an interest in this research project.

My name is Barbara Horrell and I am a Masters Thesis student in Health Psychology, at Massey University. My supervisor is Dr. Christine Stephens of Massey University. You can contact us by writing to the address above, e-mailing me at barbarahorrell@yahoo.com, or Dr. Stephens at C.V.Stephens@massey.ac.nz, or by telephoning **0800 167 266**

This letter is to provide information about our study of end-of-life care and to invite you to participate. You may choose whether or not to take part. If you would like to take part, please telephone using our free phone number above, before the end of September 2008.

What is the study about?

The aim of this study is to understand more about the experience of end-of-life care in a rural community. The study is being undertaken as part of the requirements of the Master of Arts thesis at Massey University.

Potential Benefits

The study provides the opportunity for people to talk about their own experiences and to make suggestions that might assist with the planning of rural end-of-life care. Therefore, it is anticipated that this study will be of benefit to people both receiving and providing end-of-life care. In addition, we hope that participants will benefit from the knowledge that their stories may help other rural people in the future.

Who will take part in the study and what will they do?

You will be eligible to participate if within the last 18 months you have cared for a person with a terminal illness, who was over the age of 65 and residing in the []. Up to 12 people will participate in the study, which will take place over a period of approximately 10 weeks. If you would like to take part, you will be invited to describe what the experience was like of providing care. In particular, I am interested to know what your experience of caring was like from the perspective of a person living in a rural area. For example, we may discuss the kind of support and information you needed or received. We may also discuss plans and choices you may have had. Above all, this will be an opportunity for you to tell me your story. The interviews will last about one hour and will be recorded.

You may choose where the discussions take place, either in your own home or in an interview room. I will follow up during the following week to ensure that you are comfortable with how the discussion went.

Please note that I am not a health practitioner and so am not in a position to provide any ongoing support or counselling. Should you find the interview in any way distressing or upsetting, support is available through the Otago Community Hospice Rural Outreach Service. If you are part of this service, Clare Greensmith is the Patient and Family/Whanau Support Services Director and may be contacted on (03) 473 6005. If you are not part of the service, Clare can discuss other options available to you.”

What can participants expect?

Participation is entirely voluntary: it is your choice. If you do participate, you have the right to:

- decline to answer any particular question(s)
- withdraw from the study at any time, prior to the writing up of the thesis, without giving a reason
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used, unless you give permission to the researcher
- be given access to a summary of the project findings when it is concluded

- ask for the tape to be turned off at any time during the interview
- You may invite a friend, family or whanau member to help you understand the risks and/or benefits of this study and any other explanations you may require
- You may invite a support person to be present with you during the interview

What will happen to the information?

- The discussions will be recorded and transcribed.
- You will be invited to read the transcript of your interview and suggest any changes or deletions, before the results are written up.
- Once the study is complete, you will be offered a summary of the results for all the participants if you wish.
- The results will be published as a Masters Thesis.
- They may be reported to scientific, medical and government policy meetings, and published in relevant journals.
- We will do everything possible to ensure that your contributions to these summaries and reports remain confidential. Therefore, no material or direct quotes which could personally identify you will be used in any reports.
- All digital data will be destroyed after transcription.
- Transcriptions will be securely stored for ten years and then destroyed.

Where can I get further information?

This study has received ethical approval from the Lower South Regional Ethics Committee. If you have any questions or concerns regarding your rights as a participant in this research study, you can contact an independent health and disability consumer advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

If there is a specific Maori issue or concern, please contact Koa Mantell, telephone 03 439 4456.

If you have any questions about the study in general, please feel free to contact Barbara Horrell or Christine Stephens using the contact details above.

If you would like to participate, please phone me on **0800 167 266** to arrange an interview time. I look forward to speaking with you again.

Yours sincerely
Barbara Horrell

Appendix E

Consent Form Talking about end-of-life care

I have read and understood the information sheet dated June 16, 2008 for volunteers taking part in the study of end-of-life care in a rural setting. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

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

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time, prior to the writing up of the results.

I understand that my participation in this study is confidential and that the researcher will do everything possible to ensure confidentiality in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have questions about this study.

I consent to my interview being audio-taped. YES / NO

I wish to receive a copy of my transcript. YES / NO

I wish to receive a summary of the results. YES / NO

I _____ (full name)

hereby consent to take part in this study.

Date

Signature

Full name of Researchers:

Dr. Christine Stephens Contact telephone number: 06 356 9099 extn: 2071

Barbara Mary Horrell Contact telephone number: 0800 167 266

Project explained by Barbara Horrell

Signature

Date

Appendix F

“Talking about end-of-life care”

Demographic Information

Gender Male

Female

Age 20-29 30-39 40-49 50-59 60-69 70-79 80+ (*please circle*)

Which ethnic group do you belong to?
Mark the space or spaces which apply to you.

- NZ European
- Māori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- other (such as *DUTCH, JAPANESE, TOKELAUAN*). *Please state:*

Ko tēhea momo tāngata e whai pānga atu
ana koe? *Tohua te katoa o raro nei e hāngai
ana ki a koe.*

- Pākehā
- Māori
- Hāmoa
- Māori Kuki Airani
- Tonga
- Niue
- Hainamana
- Īnia
- tētahi atu (pērā i *TATIMANA, HAPANĪHI, TOKELAU*). *Tuhia mai:*

(Source: 2006 New Zealand Census)

Appendix G

Demographic Information

		n	%
Age	20-29		
	30-39		
	40-49	1	14
	50-59	2	29
	60-69	1	14
	70-79	3	43
	80+		
	Ethnicity	NZ European	6
Maori		1	14
Samoan		1	14
All other groups		0	0
(from the 2006 census)			
Gender	Male	0	0
	Female	7	100

Appendix H

Transcription Symbols

[]	[name of town]	Square brackets indicate information has either been deliberately omitted (empty brackets), inserted for clarity or changed to maintain confidentiality
...		An ellipsis indicates where two separate conversations on the same topic have been joined together with the intervening talk omitted
[B: [So your J: [People brought me B: [neighbours and your friends	Left brackets indicate overlapping of current speakers talk by another speaker
(.)		A dot in parentheses indicates a tiny gap
(...)		Extra dots indicate a longer gap but less than a second
(2)	Um (2)	Numbers in parentheses indicate elapsed time of a second or more
—	<u>every</u>	Underlining indicates emphasis
()		Empty parentheses indicate the transcribers inability to hear what was said
(word)		Parenthesised words are possible hearings
(())		Double parentheses contain transcribers/authors descriptions rather than transcriptions
☺		Smiley face indicates a phrase spoken with a smile on the speakers face

Source: Silverman (2004)